HesaMag #18

Work-related cancer: emerging from obscurity
Cancer and work
Understanding occupational cancers and taking action to eliminate them
Edited by Tony Musu and Laurent Vogel

Accounting for more than 100,000 deaths a year in the European Union, cancers caused by working conditions constitute the main cause of mortality associated with a lack of prevention. All such cancers could be avoided through eliminating the risks found in production processes.

The potential for preventing occupational cancers and thereby reducing social inequalities in health is immense, but the path is strewn with rocks. Employers are set against any form of workplace control by Labour organisations and public authorities, while attaching greater priority to profit than to workers' health. Reviewing the current state of knowledge, prevention practices, the evolution of European legislation and the recognition of cancers as occupational diseases, this edited volume is published concomitantly with the revision of the European Directive on carcinogens.

2018 Prescrire Prize awarded to an ETUI publication

The ETUI was announced as one of the winners of the 2018 Prescrire Prize in Paris on Thursday, 4 October 2018 for its publication entitled Endocrine disruptors: an occupational risk in need of recognition. These awards have been given out every year since 1989 by the French journal Prescrire, renowned for its work on drug research and its independence from the pharmaceutical industry.

The authors of the publication are the Belgian journalist Marie-Anne Mengeot along with Laurent Vogel and Tony Musu, who are both researchers at the European Trade Union Institute.

Pierre Frouard GP, a member of the Prescrire editorial team, described the ETUI guide as 'both scientifically sound and accessible to a wide audience'.

Prescrire has some 27,000 subscribers, mostly physicians, pharmacists and other healthcare professionals.

Denis Grégoire, editor of HesaMag since its creation in 2009, is leaving the European Trade Union Institute, where he has worked since 2005. He has played an instrumental role in the design and production of the magazine, bringing to it his journalistic experience as well as his commitment to in-depth investigative work and engagement in the labour movement. He will become a trade union officer for the Confederation of Christian Trade Unions (CSC) in the Namur province of Belgium. The ETUI would like to express its gratitude to Denis for his enthusiasm and creativity. We will ensure the continuation of HesaMag, which represents a unique initiative amongst media publications dedicated to labour issues.
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Monsanto ordered to pay €254 million to gardener living with cancer

On 10 August, a Superior Court jury in California granted Dewayne Johnson, a gardener, $289 million (€254 million) in damages from Monsanto for its Roundup weed killer having caused his cancer.

Johnson’s lawsuit against Monsanto was the first case to go to trial in the US in a string of legal complaints alleging the glyphosate-based herbicide Roundup causes non-Hodgkin’s lymphoma.

Johnson sprayed Roundup and another Monsanto product, Ranger Pro, as part of his job as a pest control manager at a San Francisco Bay Area school district.

He developed a bad rash and was diagnosed with lymphoma in 2014, when he was 42.

The jurors in the Superior Court of California, who deliberated for nearly three days, found that Monsanto failed to warn Johnson and other consumers about the risks posed by its weed-killing products.

“The jury found Monsanto acted with remorse and oppression because they knew what they were doing was wrong and doing it with reckless disregard for human life,” said Robert F. Kennedy Jr., a member of Johnson’s legal team.

Monsanto, for its part, vehemently denies a link between glyphosate and cancer, frequently pointing to studies that have found the active ingredient in Roundup is safe. The St. Louis-based agribusiness giant has appealed against the verdict.

Glyphosate, however, was classified as a probable human carcinogen three years ago by the International Agency for Research on Cancer, a wing of the World Health Organization.

Over 4,000 cancer patients are suing Monsanto in numerous state courts for failure to warn the public about the risk of cancer associated with glyphosate-based weedkiller RoundUp.

In the European Union, a French court found in 2012 Monsanto guilty of chemical poisoning of Paul François, a farmer who had used the herbicide Lasso, a trade name for alachlor, an herbicide from the chloroacetanilide family. In 2015 a French appeals court upheld the ruling and ordered the company to “fully compensate” the grower.

Spain: cleaning ladies’ illnesses to be recognised by health insurers

In early September, representatives from the Spanish ministry for employment, the regional health authorities and the cleaning sector, have reached an agreement for a series of complaints experienced by hotel cleaning ladies to be recognised as occupational illnesses. Those health problems include carpal tunnel syndrome, bursitis, epicondylitis, as well as inflammations and pains in the hands and arms, resulting from the repetitive movements performed throughout the working day.

The directorate general for social security, a body within the Spanish ministry for employment, will now issue a resolution so that health insurance companies apply the recognition of these occupational illnesses as soon as possible. Meanwhile a decree will be voted on which will add these complaints to the list of occupational illnesses recognised by the country’s social security framework.

This progress represents a victory for the association of hotel cleaning ladies, who have given themselves the name Las Kellys (which comes from the Spanish las que limpian, meaning “those who clean”), and believe their cause has been left behind by trade unions over recent decades. Two years ago, these women decided to take the fight on themselves, mobilising on social media and organising protests in front of hotels to denounce the worsening of their working conditions, increasingly intensive work rates and falling wages.

Diesel emissions will fall under the scope of the Carcinogens directive.

On 11 October, the European Parliament and Council came to an agreement on the Commission’s second proposal to broaden the list of recognised cancer-causing chemicals in the workplace. Eight additional substances will be covered by the Carcinogens and Mutagens Directive, including diesel engines exhaust emission (DEEE) in workplaces. The European Trade Union Confederation has welcomed the announcement.

The binding occupational exposure limit (BOEL) for DEEE will be set at 0.05 mg/m³. It will be calculated on the basis of elemental carbon. A transition period of two years will apply to all sectors with an additional five years applying to underground mining and the construction of tunnels.

“The compromise is a victory for the European trade union movement. It is step forward in our long-standing and on-going battle for eliminating work-related cancers but existing EU legislation still needs many improvements. One of the important challenges is to include reprotoxic substances. We urge the Commission to propose a legislative initiative in 2019”, has commented Esther Lynch, the ETUC Confederate Secretary dealing with health and safety at work.

The decision will affect 3.6 million workers in the EU and prevent at least 6,000 deaths per year from lung cancer. The agreement will be submitted to the Council’s Permanent Representatives Committee (Coreper) for approval. Once the Member States’ Permanent Representatives confirm the agreement, it will be subject to a vote by the plenary of the European Parliament.
Significant reduction in employment rate five years after cancer diagnosis

On 20 June the French National Cancer Institute (INCa) and the French National Institute of Health and Medical Research (Inserm) published the results of a study carried out in France in 2015 of 4,179 people between the ages of 23 and 87 who had been diagnosed with cancer five years previously. The study focused, in particular, on the disease’s impact on their working lives.

In five years the employment rate among the cancer victims had fallen by more than 10 points, from 87.3% to 75.9%. “Given that those on sick leave are deemed to be employed from an administrative point of view, one in five people are not working five years after being diagnosed with cancer”, say the authors of the study.

Those most likely to have to give up work are manual workers, private sector employees, individuals working in very small companies, younger and older employees, company directors, and people who have been diagnosed with lung cancer, cancers of the upper aerodigestive tract or colorectal cancer.

The study also revealed that more than a quarter of those diagnosed in 2010 had seen a decrease in their disposable income five years after diagnosis, especially those in the most vulnerable sectors of the labour market (women, workers with second-level qualifications, self-employed workers). They frequently live alone and say that they suffer from aftereffects of the disease and/or its treatment.

The participants in the study were also asked about the measures taken by their employers to facilitate their reintegration: 62.7% had had their working time reorganised. This was most common among women, people who had initially been employed on a full-time basis, public sector workers and those with permanent contracts.

More than 3 million people in France live with cancer today or have suffered from it.

Gig economy drivers and riders at heightened risk of traffic collisions

The pressures that come with being a self-employed courier or taxi driver may significantly increase the risk of being involved in a collision, a new report by UCL (University College London) finds.

The majority of those surveyed – 63% – are not provided with safety training on managing risks on the road. Sixty-five per cent said that they are not given any safety equipment such as a high visibility vest and over 76% resort to providing their own.

Dr Nicola Christie and Heather Ward (UCL Centre for Transport Studies) carried out 48 qualitative in-depth interviews with drivers, riders and their managers, and analysed 200 responses to an online survey taken by drivers and riders. The participants included self-employed couriers who delivered parcels and food, and self-employed taxi drivers who received their jobs via apps.

Over two in five (42%) of drivers and riders reported that their vehicle had been damaged as a result of a collision while working, with a further one in ten reporting that someone had been injured. Eight per cent reported that they themselves had been injured, with two per cent saying someone else had been injured.

“Our findings highlight that the emergence and rise in the popularity of gig work for couriers could lead to an increase in risk factors affecting the health and safety of people who work in the gig economy and other road users,” explained Ms Ward.

“As more workers enter the economy and competition rises, the number of hours they need to work and distances they must travel to earn a stable income both increase. We know this is an issue but don’t know exactly how far it extends as not all companies need to report the number of self-employed couriers they use to the government.”

The UCL report, The emerging issues for management of occupational road risk in a changing economy: A survey of gig economy drivers, riders and their managers, includes a list of recommendations for companies using self-employed couriers and taxi drivers to limit the pressure drivers and riders are under.

Mobile phones should not be allowed to cause a distraction, after the results showed that 40% of those using an app found them to be off-putting whilst driving or riding. Most of the surveyed couriers on scooters, motor and pedal bikes reported receiving work through an app which played a noise at intervals to alert them to a job with a fixed time window in which to accept.

Other risk points for drivers and riders include tiredness – particularly among parcel couriers – from overwork and the intense pressure of self-employed parcel delivery, with many reporting regular near misses and collisions.

Participants say they are more likely to take risks such as speeding or going through red lights to save time.

Chemical risks: French report wants improved employer monitoring

In early September the French Ministry of Labour published a report on the prevention of chemical risks at work. Written by Paul Frimat, a professor in occupational health, this document had been tucked away for several months because it contains several proposals that go against the reforms undertaken under the presidency of Emmanuel Macron.

Those reforms aim to reduce employers’ obligations in terms of risk prevention. By contrast, the Frimat report calls for increased employer accountability and recognition of occupational diseases due to dangerous chemicals.

It therefore proposes allowing labour inspectors to impose fines where chemical risk obligations are not met and to “extend the temporary cessation of activity procedure” in cases where a business does not comply with essential prevention measures.

The author makes another notable recommendation that is not strictly work-related: he advocates “taxing manufacturers of the most dangerous products”. He also stresses the need to “add to the (obsolete) list of work involving dangerous chemicals that people on fixed-term or temporary contracts are prohibited from carrying out”.

Professor Frimat adopts the idea of a bonus-penalty system as part of the workplace accident-occupational disease contribution paid by employers to health insurance companies. The current system already takes account of the business’s results in terms of occupational health and safety, but only to a limited extent.

He also proposes creating an employer record that will improve traceability of workers’ exposure to dangerous substances. Given that the proportion of cancers attributable to occupational factors remains understated and weighs on the social security budget, improving traceability would also help with recognising work-related pathologies. The report underlines that diseases are often reported years later, which means that it is “very difficult to prove the worker’s exposure”.

He also recommends making occupational disease tables “more flexible”, by introducing the possibility of additional tests allowing work-related causes to be better identified.

In France, a survey has estimated that 2.2 million employees come into contact with at least one carcinogenic chemical, i.e. around one employee in ten. 
**United States: investigation lifts the lid on working conditions for prisoners employed in the poultry industry**

Following the death of a prisoner in a workplace accident that occurred in October 2017 in an Alabama poultry plant, a US NGO has investigated the working conditions of US prisoners selected for work release programmes.

The Southern Poverty Law Center (SPLC) estimates that dozens of businesses in the poultry sector in at least seven states have used 600 prisoners or more in recent years.

Like their non-prisoner “colleagues”, these prisoners face particularly tough working conditions. Production targets are regularly set at 140 carcasses per minute. Work rates like these result in multiple accidents. The sector has an injury rate that is almost double the national average, and 72% of survey respondents confirmed having suffered serious injuries or illnesses linked to their work. Workers in the poultry sector fall ill six times more often than the average for the US working population. Among those workers assigned to disinfection tasks in poultry abattoirs, national and European statistics confirm that employees in this sector are regularly set at 140 carcasses per hour.

The NGO has calculated that, since 2001, there have been at least 24 incidents in the states of Georgia and North Carolina resulting in injuries to prisoners employed in the poultry industry.

The main benefit for prisoners of working in the private sector is the opportunity to earn an hourly wage, at least on paper. However, according to the SPLC, although minimum wages apply to prisoners, once costs and other deductions have been taken by the Alabama Department of Corrections, workers often find themselves with only 13 cents of every dollar earned.

**People who work nights and shifts at higher risk of workplace injury**

Night workers, shift workers and new recruits are at a higher risk of workplace injury, compared to staff not working these hours, according to a study published in April 2018 by the Health and Safety Authority (HSA), the national body in Ireland with responsibility for occupational health and safety.

The rate of fatalities is highest in the agriculture, forestry and fishing sector. It was the only sector to see an increase in fatalities in the 2001 to 2014 period. The number of fatalities increased from 129 in the 2001-2007 period to 151 in the 2008-2014 period. The combined fatalities in industry, construction, transport, and agriculture, forestry and fishing accounted for 85% of all worker fatalities in Ireland in 2014.

The authors of the study pointed out that longer working weeks are associated with injury. Construction sector workers working between 40 and 49 hours a week faced a greater likelihood of injury per hour worked.

In terms of illnesses, musculoskeletal disorders continue to be the main reported disorder. Significantly, the rate of musculoskeletal problems rose during the recession. They accounted for some 46% of cases in the health sector, while stress, anxiety and depression were also more common illnesses in health (22%) than in other types of employment (16%).

The study has also shown that the health sector has the most days lost per worker to due to work-related illness. In this sector, 524 days were lost per 1,000 workers. This was followed by transport (507), agriculture, forestry and fishing (358), industry (351) and was lowest in construction (313).

“Our research shows that new recruits in construction, health, agriculture and transport have a significantly higher risk of occupational injury”, commented Helen Russell, the lead author of the study. “Hence, there is need for supervision, training, and support to prevent rising injury and illness rates”, she added.

**Employers and unions call on Commission to include reprotoxicants in the Directive on carcinogens and mutagens at work**

On 16 October the European chemical industry and trade unions agreed that European Union (EU) workers should be better protected from the risks related to exposure to reprotoxic substances. In a joint declaration, the European Trade Union Confederation (ETUC), the industriAll European Trade Union, the European Chemical Employers Group (ECEG) and the European Chemical Industry Council (Cefic) called on the European Commission to extend the scope of the Directive on the protection of workers from carcinogens and mutagens to reprotoxic substances.

"In our view, one EU directive covering carcinogens, mutagens and reprotoxicants at the workplace would be a solid basis for harmonised EU wide minimum requirements", declared the trade unions and employers’ organisations in their joint declaration.

The chemical industry employers and unions propose adopting Binding Occupational Exposure Limits (BOELS) for reprotoxic substances, as is the case for an ever increasing number of carcinogens and mutagens. The document suggests that the Commission make a distinction in the future between carcinogens or reprotoxicants for which it is possible to define an exposure threshold below which no adverse effect on health is expected and those for which it is impossible to set a safe level.

For carcinogens or reprotoxicants without a threshold, the chemical industry employers and unions propose continuing to apply the “exposure minimisation principle”. This means that enterprises that expose their workers to carcinogenic or reprotoxic substances of this type should further reduce exposure levels below the BOELS defined in the new directive.

The chemical industry has long been opposed to the trade union demand for the Carcinogens and Mutagens Directive to be extended to reprotoxicants. The change in the employers’ position is no doubt connected with the fact that an increasing number of Member States have decided in recent years to include reprotoxicants in their national legislation on the prevention of carcinogenic and mutagenic risks at work. The manufacturers clearly want to avoid being subject to different obligations in the various countries in which they operate. They also consider that these changes would bring this occupational health legislation into line with all the other European legislation on chemicals (REACH, biocides, cosmetics, etc.), which applies the same rules to carcinogens (C), mutagens (M) and reprotoxicants (R) in what is commonly known as the group of CMR substances.
Soumaila Sacko was assassinated in San Calogero on Saturday evening, 2 June 2018. 29 years old, born in Mali and working on a farm in Southern Italy, he lived together with some 5,000 other day labourers from Africa in one of the ramshackle settlements dotted around the plain of Gioia Tauro, an agricultural region in Calabria. Together with two of his mates, he’d gone over to an old factory building in San Calogero, where his friends were looking for corrugated iron sheeting to patch up their “homes”. Soumaila wanted to give them a hand. He was in the bad books of the region’s farm-owners and their henchmen, the “caporali” tasked with hiring the day labourers and often with links to criminal organisations. Why was he in their bad books? Because he was a trade union activist. He had thrown himself into organising the African day labourers, all of them subject to terrible exploitation. Exhausting days spent picking what the fields produced for 2 Euros an hour. Camped out in primitive accommodation, often without even the most basic sanitary facilities. Daily humiliation and violence.

Three days before his murder, a new Italian government had just been formed after lengthy negotiations, a coalition between the extreme right Lega party and the Five Star Movement. Its programme took the unusual form of a notarial contract signed by the respective two leaders, Matteo Salvini and Luigi Di Maio. Mimicking how things are done in the private or commercial sector, to a large extent this “contract” reflects the xenophobic and racist obsessions nourishing extreme right parties nearly everywhere in Europe. For example, it provides for the establishment of detention centres for migrants without papers in all regions of Italy. It even quantifies who is to be targeted by the new government; 500,000 migrants to resign themselves to their fate, to get on with their work and to keep their mouths shut.

The assassination of Soumaila Sacko was followed by protest rallies and strikes by Southern Italy’s African farm labourers. The silence of the members of the new government was deafening. For several days, neither the Minister of the Interior, Salvini, nor the Minister of Work, Di Maio – the two signatories of the “contract” – were to issue any statement. The day after the assassination, Salvini was to be heard triumphantly addressing a meeting in Sicily: “The party is over for all illegal migrants. They’ll have to pack their bags, without haste, but their time is up.” Even the repatriation of the corpse to Mali was only possible through a collection organised by the union. The writer Roberto Saviano has replied to the new Italian leaders: “For someone who landed at night in Italy and gained a residence permit, the party was over on a Saturday evening when helping his mates get hold of some corrugated iron sheeting to build a fire-resistant shelter. The end came quickly – a bullet in his head. Soumaila Sacko died, in Calabria, just a few kilometres away from Rosarno, the small district where Salvini was elected senator. Soumaila had a valid residence permit. I can’t dare imagine what the end of the party is going to be like for those without papers.” Indeed, for several years now, various NGOs have been reporting the murders of migrant day labourers who have dared to stand up against their bosses. In many cases, the corpses have disappeared without trace.

In the weeks following the assassination of Soumaila Sacko, the Italian press focused on the scene of the crime. Inaptly named, the fornaice tranquilla, (the “tranquil furnace”), a former construction material factory, is probably the most dangerous site for illegal dumping in Europe. Some 130,000 tonnes of carcogenic materials are buried there, enabling the companies concerned to save the cost of more effective treatment. Even though the scandal was unearthed in 2011, legal proceedings have been bogged down for years. Among the companies responsible for this crime against public health is the Italian electricity company ENEL, a former state enterprise privatised in 1999. This helps explain the complacency with regard to certain forms of illegality. Between 2000 and 2007, no less than 4,500 lorries arrived at the site, right in front of the (closed) eyes of the authorities.

The person behind the assassination, Antonio Pontoriero, is one of the region’s farm-owners. His uncle is cited in the toxic waste lawsuit as a go-between between the owners of the fornaice tranquilla and the companies sending their waste there.

As in a Greek tragedy, San Calogero possesses all the ingredients of two possible destinies for Europe. The inhuman working conditions of migrants made possible by government refusals to grant papers to most of them, racist hate, the quest for profit as a value shared by organised crime and multinational companies, the dramatic rise of xenophobic parties in many countries and their inclusion in governments in a number of them. Soumaila Sacko symbolises the possibility of a different future, that of humanity without borders, of solidarity and the collective fight for emancipation.
The world of EU lobbying in Brussels

Brussels is the lobbying capital of Europe. And with so many of our national laws starting life at EU level, it is not difficult to see why. Big corporations, industry lobby groups, lobby consultancies and law firms spend hundreds of millions of euros every year to ensure that EU policymaking meets the needs of big business – and it very often works.

Olivier Hoedeman
Corporate Europe Observatory (CEO)
It is estimated that there are over 25,000 lobbyists working in the European Quarter, most of them in the service of corporations and their lobby groups. Whenever the European Commission proposes a new regulation or the European Parliament votes on a new law, corporate lobbyists are there, outnumbering and outsending public interest groups. On some issues the imbalance is staggering. In the lobbying concerning EU financial regulation, the banking sector is outsending NGOs, trade unions and other interest groups by 30:1.

Larger numbers of lobbyists and large lobbying budgets combined with privileged access to decision-makers often result in excessive industry influence and the corporate capture of decision-making. One example of such privileged access is when corporate lobbyists dominate membership of the Commission’s many advisory groups, or so-called expert groups. This dominance can easily result in biased advice, with very negative impacts on draft EU legislation.

Research by watchdog groups has revealed that 75% of the lobby meetings of Commissioners and high-level Commission officials are with lobbyists representing big business. In such key areas as financial regulation, the internal market and international trade policy, this figure rises to over 80%.

The revolving door is another important way in which industry gains the upper hand in the battle to influence the political agenda in Brussels. When senior European decision-makers – Commissioners, MEPs, officials – leave office and go straight into lobby jobs, or when lobbyists join the EU institutions, the risk of conflicts of interest and undue influence is great, undermining democratic, public-interest decision-making. And the revolving door spins fast in Brussels. One third of Commissioners leaving in 2014 went into industry lobbying jobs. Commission President Barroso’s move to Goldman Sachs and Commissioner Neelie Kroes’ switch to Uber and Bank of America were among the most controversial revolving door cases.

A fundamental problem behind the privileged access enjoyed by big business lobbyists is the widespread belief in neoliberal ideology within the EU institutions, a set of beliefs that is centred around free markets, deregulation and the idea that what is good for big business is good for society. This approach has an inherent risk of enabling the corporate capture of decision-making.

The lobbying battle around glyphosate

Many of these problems were clearly present in the battle over the revision of the EU’s market authorisation for glyphosate, the world’s most widely-used herbicide and a key ingredient in Monsanto’s Roundup weedkiller. But the intense lobbying battle around this decision also shows that when large numbers of EU citizens manage to get mobilised, industry lobby groups do not always win on all fronts.

In the past, the decisions over market authorisation for glyphosate were taken quietly in meetings of little-known EU committees, without any public attention. This time, however, the glyphosate re-authorisation process took place at a time when concerns about the pesticide’s health impacts had grown substantially, with the World Health Organisation’s cancer institute declaring the substance as “probably causing cancer to humans”. Had the EU come to the same conclusion, this would have resulted in a once-and-for-all ban of all Roundup products, as EU pesticide rules ban all active ingredients capable of causing cancer, disturbing the hormonal system or having a toxic effect on the reproductive system.

Civil society petitions for phasing out glyphosate were supported by hundreds of thousands of citizens from across Europe. There were demonstrations and events outside key meetings of the EU officials deciding on the future of glyphosate. Over a million citizens signed a European Citizens’ Initiative to urge the European Commission to ban glyphosate, not only for health reasons but also for the large-scale environmental damage caused by the product.

The corporate agri-food sector boasts very powerful players in the “Brussels Bubble”, all with privileged access to top decision-makers. Tactics include PR stunts, fancy conferences, media greenwash, networking events for policy-makers and journalists, as well as the ‘revolving door’ recruitment of former public officials to the private sector. The pesticide industry is used to quietly using its privileged access to influence EU decision-makers. But in the glyphosate battle, industry faced an unprecedented challenge from concerned citizens. Pesticide giant Monsanto is a prime example of a corporate giant that gives precedence to below-the-radar lobbying, with its campaigns relying heavily on industry coalitions and front groups. One example is the Glyphosate Task Force, which is run from the offices of lobby consultancy firm Hume Brophy based in the European Quarter. Monsanto also hired a number of other lobby consultancy firms to help derail restrictions on glyphosate. The most visible lobbying was done via pesticide industry coalition ECPA, which for example organised a lobbying dinner with members of the European Parliament the evening before a crucial Parliament hearing.

The glyphosate battle further intensified in 2017 after thousands of pages of internal Monsanto documents were published, released in the context of a US court case against the company started by cancer victims. The Monsanto Papers show that the company hardly tested the real-world toxicity of its products, actively avoided pursuing studies which might show unwelcome results.
and ghostwrote the studies of supposedly independent scientists. The documents also show that Monsanto systematically attacked scientists whose research threatened their profits. The evidence of Monsanto’s manipulations of science and the regulatory process was so shocking that the European Parliament voted in favour of phasing out glyphosate. National governments have by now become another major focus in the pesticide debate, the next re-approval process – as well as that of many other pesticides – will be very closely scrutinised from the outset by citizens, politicians, the media and scientists. Meanwhile, many EU member states have introduced further restrictions on the use of glyphosate-based products, including a ban on all glyphosate-based herbicides in Belgium.

Corporate capture and what to do about it

The glyphosate battle shows how deeply rooted the influence of the pesticide industry is in EU decision-making. It also shows that strong citizen mobilisation can break open the debate and achieve significant impact. Another key factor in the battle is the fact that the deeply manipulative strategies of Monsanto and other pesticide producers

Corporate Europe Observatory (CEO) is a research and campaign group working to expose and challenge the privileged access and influence enjoyed by corporations and their lobby groups in EU policy making. If you visit Brussels, join one of the guided ‘lobby tours’ of the European Quarter regularly run by our team, during which we provide either a general introduction to the lobbying scene or give a thematic tour looking at specific industries. CEO also offers workshops on investigating corporate lobbying, introducing simple research tools and how you can use them in your campaigns.

__For more information__
https://corporateeurope.org/lobby-tour-request

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and ghostwrote the studies of supposedly independent scientists. The documents also show that Monsanto systematically attacked scientists whose research threatened their profits. The evidence of Monsanto’s manipulations of science and the regulatory process was so shocking that the European Parliament launched a special investigation committee on the Monsanto Papers. The Parliament’s high-level Monsanto Papers hearing became a target of heavy lobbying itself, by pesticide industry lobby groups and national farmer unions. Another result of the controversy around Monsanto was the lobby ban imposed by the European Parliament, with MEPs voting to ban Monsanto from entering Parliament premises after the company had refused to testify at a parliament hearing.

The unprecedented public debate and high-profile political controversy around the renewal of glyphosate authorisation also helped expose the wider flaws in the EU’s regulatory framework for the risk assessment of pesticides, and in particular the role of EFSA, the EU food safety agency. EFSA’s recommendations are to a large extent based on secretive industry data rather than independent scientific studies. CEO and the European Greens asked EFSA for access to the Monsanto studies upon which EFSA based its advice. The studies were eventually released to them, but can still not be published online to be scrutinised by any expert who might wish so.

 Shockingly, the pesticide industry had advance access to EFSA’s safety assessment of glyphosate. Shortly before the agency revealed its 2015 safety assessment, industry representatives were asked to file requests for text amendments and were even able to edit the documents at the very last minute. The good news is that the European Parliament’s special committee on the Monsanto Papers is set to propose significant improvements to the EU’s regulatory policies, to the benefit of public health and the environment and at the expense of agribusiness corporations. Also, following the European Citizens initiative to ban glyphosate and protect people and the environment from toxic pesticides the European Commission responded to one of their demands, promising transparency of all (industry) studies used in approvals of all regulated products. However, the devil is in the detail and this is currently an ongoing battle in the European Parliament.

The public debate and controversy had an impact. In the final stage of decision-making, the European Parliament voted in favour of phasing out glyphosate. National governments were deeply divided and a series of meetings of a so-called comitology committee in Brussels repeatedly failed to reach agreement. At the end of 2017, the European Commission backed down, proposing a five-year extension of market approval for glyphosate for agricultural use instead of the originally planned 15 years. Nine governments voted against extending the approval, but a majority of EU member states supported the Commission’s proposal, following heavy industry pressure on national governments. The German vote, for instance, scandalously changed at the last minute from abstention to a ‘yes’, going against the agreement reached between the relevant ministers! The next review of glyphosate is set to start in two years’ time. Since the extremely harmful impacts of pesticides in general on biodiversity have by now become another major focus in the pesticide debate, the next re-approval process – as well as that of many other pesticides – will be very closely scrutinised from the outset by citizens, politicians, the media and scientists. Meanwhile, many EU member states have introduced further restrictions on the use of glyphosate-based products, including a ban on all glyphosate-based herbicides in Belgium.
have been exposed and their legitimacy undermined.

It’s one thing to get one pesticide banned, but it’s another thing to achieve a vast reduction in the overall use of pesticides. Indeed, beyond individual lobbying battles, a deeper change is needed to prevent excessive corporate influence. Until EU decision-makers stop conflating the interests of big corporations with those of the public, profit will come before climate and public health.

If we want policies reflecting the interests of corporations with those of the public, profit will come before climate and public health. A lobby group for the agrochemical industry, ECPA aggressively pushes for weak regulation of pesticides and GMOs. It represents transnational pesticide manufacturers such as Syngenta, Monsanto, BASF, Bayer CropScience and Dow AgroSciences. The association has a significant presence within the EU institutions and is a member of a large number of advisory committees and expert groups in the agricultural, health, and environmental sectors.

ECPA and its US counterpart, CropLife America, lobbied for their industry to get the most out of the EU-US trade and investment negotiations (TTIP). Luckily for them, both US and EU negotiators were happy to work closely with the pesticide industry to ensure that TTIP “minimises their costs and burdens” even if this means increasing risks to human health and the environment. Both associations were pronounced the joint winners of the 2016 Democracy for Sale awards (co-organised by Corporate Europe Observatory) for their attempt to use the TTIP talks to shape current and future pesticide regulation.

BAYER
Declared lobbyists: 12.25 FTE
Lobby spend: €1,948,000 (2016)

Bayer recently took over Monsanto in a $66 billion deal. This German chemical and pharmaceutical company has a long history of controversy that looks set to continue. From its belle époque promotion of heroin as a cough treatment for children, to more recent pushes for lax GMO and pesticide regulation in Europe, Bayer cannot seem to resist getting its paws on even the hottest of political potatoes.

A dominant player in the neonicotinoid pesticide market, Bayer came out all guns blazing against reports on the potential harmful effects of its products on bee populations. Neonicotinoid pesticides are absorbed into plants as they grow and can seep into nectar and pollen where it is thought to harm and kill pollinating insects. Along with other pesticide companies, Bayer and the European Crop Protection Association have lobbied fiercely against EU action on ‘neonics’. Similarly, the industry went to war on a looming ban on hormone (endocrine) disruptors (EDCs). Present in everyday products, these chemicals interact with the body’s hormonal systems and are suspected of having severe health and environmental impacts. Their methods targeting EDCs included scaremongering, delaying tactics, discrediting evidence and leveraging the TTIP negotiations to stop the EU taking action to restrict EDCs.
Work-related cancer: emerging from obscurity

Special report coordinated by
Denis Grégoire and Laurent Vogel (ETUI)

Cancer is responsible for 1.3 million deaths in the European Union each year. According to the International Labour Organisation (ILO), more than 100,000 of these deaths are attributable to exposure to carcinogens during a victim's working life, meaning that nearly 8% of all cancer deaths in Europe are work-related. Yet such occupational factors only rarely attract media attention. Even more surprisingly, the campaigns rolled out by public institutions or private organisations dedicated to fighting cancer almost never speak of such causes.

Prevention messages are primarily focused on the effects of individual behaviour (smoking, eating the wrong things, not taking enough exercise, drinking too much alcohol), although environmental factors (radon, particulates in the air, pesticides) are also slowly moving into focus.

But why are they all silent when it comes to work-related carcinogens? The fact that occupational cancers mainly affect blue-collar workers in low-profile sectors (cleaning, industrial maintenance, waste recycling and treatment, etc.) explains this “invisibility” to a certain extent.

For some thirty years, the European Trade Union Institute has been engaged in researching the issue, providing information on the subject and raising awareness to work-related cancers. Its main objective is to get European legislation in this field tightened. Despite many obstacles, this work is now – finally – bearing fruit, with many occupational exposure limit values now adopted for carcinogens present in a large number of companies. But though laws play a key role in protecting workers’ health, they are nothing more than a promise – and by no means a guarantee. In all too many companies, basic health and safety rules continue to be flouted. In the vast majority of cases, these breaches of the law go unpunished. One of the only exceptions is when workers, either individually or collectively, take action themselves. But this also involves them bearing the financial, social and occupational consequences.

Without their action, the work carried out by the ETUI at EU level on occupational cancers would be a fruitless endeavour. And this is the reason why we have decided to dedicate this dossier to the individual stories of people who, to varying degrees, have dared to break the silence surrounding their diseases. On the following pages you will be reading about the struggles of French glassworker Christian Cervantes, of Esat Selimi, a Kosovan worker in Europe’s most polluting coal-fired plant, of Spanish nurse Georgina, herself hit by cancer while helping to cure it, of arborist Marc Maillan, a victim of pesticides, of Nadine whose cancer was not work-related but who had to fight to find work after being cured, and, last but not least, of textile worker Laurence Petit and her partner Christophe.
Occupational cancers: avoidable diseases engendering major costs for our societies

The primary cause of work-related mortality, occupational cancers cause high costs for workers, employers and health systems in all European countries. But it is the workers and their families who have to bear nearly all of these costs. The revision of the Carcinogens and Mutagens Directive (CMD), now relaunched, should help reduce the number of victims and the associated costs.

Tony Musu
ETUI

Blue-collar workers pay a heavy price for being exposed to carcinogenic substances at work.
Image © Matteo Di Giovanni
Christian Cervantes battled with two cancers at once: cancer of the mouth and cancer of the pharynx. Tragically, he lost the battle at the age of just 64. He had worked in the glass industry for over 30 years, where he had been exposed to several carcinogenic substances: asbestos, polycyclic aromatic hydrocarbons (PAHs), refractory ceramic fibres, solvents. He knew nothing about the risks of these exposures for his health. After a tough legal battle waged by his family, the causal link between his multiple exposure to these carcinogenic substances at work and the development of his cancers was finally recognised by a tribunal in Lyon (France).1

This case is interesting from several different aspects. First of all, it is very much representative of what are known as "occupational cancers", diseases affecting blue-collars much more than white-collars, leading to what are called "social inequalities in health". Throughout Europe, blue-collar occupations are indeed hit much more by cancers than white-collar ones, and the risk of contracting cancer is to a large extent dependent on a person's position in a company.2

These cancers are due to repeated exposure to hazardous substances without adequate protection throughout working life. In most cases, workers are not informed of the risks to which they are exposed, and the necessary measures for protecting them are not taken. The history of our production-driven societies and the quest for maximising profits shows that in certain cases this ignorance was deliberately fostered by industry leaders, as was the case with asbestos and vinyl chloride monomer and still is the case for endocrine disruptors or glyphosate.

As shown by the example of Mr Cervantes, victims of occupational cancers have most often been exposed not just to one but to a whole cocktail of carcinogens. What makes the case of this glassworker stand out however is the fact that multiple exposure has for the first time been recognised by a court as being the cause of his occupational cancers.3 In all European countries, if and when a cancer is recognised as an occupational disease, it is generally linked to just one causal agent. Multiple exposures at work are however the rule. For instance, construction workers may be simultaneously exposed to crystalline silica, asbestos, diesel engine exhaust emissions, wood dust, PAHs and to UV radiation from the sun. If they want to have their lung cancer recognised as an occupational disease, only one of these exposures will be taken into account.

Invisible diseases

Cancers are multifactorial diseases and risk factors are numerous (lifestyle, genetic factors, environmental or occupational exposure, etc.). When a cancer suspected of being work-related occurs, it is therefore difficult to establish the link to working conditions. Cancer pathologies generally have no specific signature and there is no way of distinguishing for example between work-related bladder cancer and bladder cancer with a different cause. Moreover, occupational cancers often appear dozens of years after exposure begins, typically when workers have retired. They rarely consider making the link to the work they used to perform, especially when they are unaware of the identity of or the risks associated with the agents to which they were exposed.

At the same time, doctors show little interest in the past careers of their cancer patients, rarely posing the question: "What job did you use to do?" The result is that occupational cancers are lumped together with all other cancers, not usually being identified as occupational.

1. Further reading: Marichalar P. (2018) Fighting for the factory, only to die for it. The exemplary fight of the former Givors glassworkers, HesaMag 17, Brussels, ETUI.
3. Thébaud-Mony (2018) Ensuring recognition of the cancer outcome from multiple exposures to carcinogens at work, in Musu T. and Vogel L. Cancer and work. Understanding occupational cancers and taking action to eliminate them, Brussels, ETUI.
4. Note that more than 95% of mesothelioma cases are attributable to asbestos exposure.
as work-related. This invisibility is even more the case among women, with the majority of epidemiological cancer studies referring to men. One persistent bias is that men are more affected than women because of the heavy and dangerous jobs they do in industry. However, it would seem that women are affected just as much, especially those working in certain occupations such as nursing (see box, p. 16).

Estimates state that occupational cancers represent some 8% of all new cancer cases recorded each year (for both genders) in the European Union (EU) and that they are responsible for the deaths of more than 100,000 people each year. According to the World Health Organisation (WHO), they constitute the primary cause of work-related mortality in the EU, far more than work-related accidents which lead to some 5,000 deaths a year or 20 times less. In all European countries, we are confronted with the phenomena of non-reporting and non-recognition of occupational cancers as occupational diseases. In France for example, less than 2,000 cases of cancer are recognised as work-related each year, even though the authorities themselves estimate the annual number of work-related cancer cases to be between 14,000 and 30,000. This phenomenon also fosters the invisibility of such pathologies. There are indeed many obstacles in the way of reporting and recognising such cancers. Apart from the already-mentioned difficulty of establishing the link between the cancer and the work performed by them, patients suspecting such a link often prefer to focus their efforts on fighting the disease rather than starting out on a long administrative procedure with no certain outcome for getting their cancer recognised as work-related (see box, p. 15). Many patients are even unaware that a compensation system exists and that they have access to it.

Throughout Europe, battles are being waged by workers and their families to get cancers recognised as occupational diseases and to obtain compensation. In certain cases, they manage to gain recognition through going to court. For Mr Cervantes and his family, the legal battle lasted 12 years, with the verdict in their favour pronounced 5 years after the death of this trade union member. The legal proceedings against the employer are by no means finished. In preparation of its lawsuit, the Cervantes family sent out a questionnaire to former workers of the glassworks. Among the 208 replies were 92 cases of cancer. Convinced that their pathologies are linked to the bad working conditions and the lack of protection measures, a large number of colleagues are now taking legal action against their employer for "wilful misconduct", a provision enshrined in the French Social Security Code.

**Staggering costs for victims**

In the context of the talks on revising the CMD, the European Trade Union Institute (ETUI) commissioned a study to estimate the annual cost of occupational cancers in the EU-28. The researchers started by drawing up a list of carcinogens currently considered to be responsible for the majority of occupational cancer cases in Europe. They identified twenty-five carcinogenic agents. Apart from the carcinogens already mentioned above, the list included passive tobacco smoke, hexavalent chromium, cadmium, formaldehyde, benzene as well as agents such as night or shift work or work in the rubber industry. The researchers ended up with an estimate of the annual number of cancers attributable to exposure to these 25 agents: some 190,000 new cases for all 28 EU countries (between 125,000 and 275,000 cases a year). Lung, breast and bladder cancers were the most frequent work-related cancers. When looking at all new cases of cancers reported in Europe, the share of occupational cancers accounts to 8% (6-12%) for both genders, to 5% (3-7%) for women and to 10% (6-15%) for men. These estimates are close to the higher ones found in the literature and support studies establishing the overall proportion attributable to occupational cancers at 8% or higher. Another important finding of this study is that the attributable fraction for women is higher than that estimated in previous studies. Based on the number of work-related cancer cases, the study concludes that the total cost of such cancers is between €270 and €610 billion a year for the EU-28 (corresponding to 1.8 - 4.1% of EU GDP).

These costs cover direct costs (medical treatment, transport, etc.), indirect costs (loss of productivity due to absence from work, etc.) and intangible (or human) costs for the victims (loss of quality of life for workers and their families). Looking at the break-down of these costs among the various players, we find that workers and their families bear the brunt (more than 98%), with a major share of the direct costs and all human costs borne by them. Even if excluding human costs, the direct and indirect costs remain substantial, with the ETUI study estimating them to be between €4 and €10 billion a year. Employers mainly bear the costs (some €4 billion a year) associated with the short- or long-term absence of the sick workers, as reflected in the costs of staff turnover, the training of replacements and insurance premiums. The state bears part of the medical costs, social insurance costs and the loss of human capital due to the premature deaths.

**Commissioner Thyssen can be credited for re-launching the revision of the legislation stalled for the last 25 years.**
Employers are pocketing the profits deriving from the workplace use of carcinogens, while outsourcing the largest slice of costs to the victims and national public health systems.

Recent progress

Designed to protect workers against the risks associated with workplace exposure to carcinogens and mutagens, the CMD is a key weapon in the European legislative arsenal. Adopted in 1990, it organises prevention and defines a hierarchy of employer obligations. When unable to eliminate or replace carcinogens by less hazardous substances or processes, or to use closed systems, they are obliged to reduce exposure to carcinogens and mutagens to levels as low as technically possible.

The CMD sets down occupational exposure limit values (OELs) which are not to be exceeded. For the last 25 years, the CMD has remained unchanged, with just three carcinogens being assigned an OEL. In 2016, at the instigation of a number of EU Member States and the European Trade Union Confederation (ETUC), the European Commission finally relaunched the revision of this Directive, putting forward proposals for OELs for further carcinogens. The stated target of Marianne Thyssen, the Social Affairs Commissioner within the Juncker Commission, was to have binding OELs adopted for 50 priority carcinogens before 2020. Supported by the ETUC, these amendments and, in the subsequent chance that these new OELs could be adopted by the co-legislators (the European Parliament and Council) before the end of the Austrian EU Presidency in December 2018.

A fourth batch is currently under discussion within the Commission. In its present state, it refers to three carcinogens: nickel compounds, acrylonitrile and benzene. Given the time needed for the legislative process, these new OELs are unlikely to be adopted before the European elections in May 2019 and thus the end of the mandate of the Juncker Commission. With a total of 25 carcinogens with binding OELs at EU level, Commissioner Thyssen will not be able to meet her committed target for 2020. She will also leave behind her a number of unfinished building sites, including the extension of the scope of the CMD to reprotoxic substances and the adoption of an EU-level methodology for adopting OELs for carcinogens without thresholds. Nevertheless, she can be credited with relaunching the revision of the legislation stalled for the last 25 years and, we hope, with making it durable.

This is one of the necessary conditions for establishing a true cancer prevention culture in companies, for bringing down the number of occupational cancer victims and the substantial costs they entail for our whole society.

The two systems of recognising occupational diseases

Two forms of recognition systems are used in the majority of European countries: the closed list system and the open list system. Under the first system, the patient’s disease must figure in the list and the patient must meet the predefined criteria to gain recognition (for example, having been exposed to a known causal agent for a certain number of years). These criteria are often very restrictive, meaning that numerous claims have been rejected. The occupational cancers most often recognised in Europe are those associated with asbestos (some 80% of recognised cases). Under the second system, the victim has to prove the link between his pathology and his work. It goes without saying that this system is much more complicated and has a much lower success rate (just 1% of occupational cancers recognised in Germany and 2% in France).

Further reading


Occupational cancers thus cause extremely high costs for workers, employers and social security systems in all EU Member States. Workers are the big losers, while employers come out best, pocketing the profits deriving from the workplace use of carcinogens, while outsourcing the largest slice of costs to the victims and national public health systems. One can thus well understand why they are little inclined to take effective prevention measures against occupational cancers.

To drastically reduce the number of cancers linked to bad working conditions, we urgently need the EU to come up with a proper strategy for fighting these diseases. This requires, inter alia, the updating and tightening of existing legislation and better enforcement of these rules in companies.
Breast cancer and work: overcoming the ignorance and denials

Laurent Vogel

ETUI

The many associations of breast cancer victims work to modify relations between patients and the medical world. In France, nurse Sylvie Pioli has set up such an organisation, CycloSein. But there is something special about Sylvie’s association: it aims to promote prevention through eliminating occupational risk factors. Its main preoccupation is to highlight the link between night work and breast cancer.

Sylvie herself worked for 30 years as a nurse in a hospital, often working nights. In December 2014, while under the shower, she felt a bump in her right breast. Being a nurse, she was able to see a doctor very quickly. Eight days later, she got the diagnosis: breast cancer. This meant surgery in early January 2015, 3 months of radiotherapy and 5 years of hormone therapy. Like many patients, she wondered how she could have contracted the disease. There was no specific risk factor able to explain her cancer. Speaking with the anaesthetist on the day of her surgery, she was told: “No need to look further. Breast cancer and night work go together.”

After having gone through the successive therapies, she has now started rebelling against the system. In 30 years, nobody had ever told her about the cancer risks associated with night work. Sylvie began to discuss the matter with others. She became a critical patient, not hesitating to question doctors on the limits of their knowledge. She became an avid reader of the scientific literature. One of the articles she found was about the CECILE study, the results of which showed that the risk of breast cancer was 30% higher among women doing night work. This increased risk is marked among women having worked nights for more than four years, or among those whose work schedules involve working at least three nights a week, i.e. frequent changes between day and night shifts.

I met Sylvie at a trade union training course devoted to the role of working conditions in the development of breast cancer. It quickly became clear that associations and trade unions need to learn a lot from each other if they want to develop effective prevention action.

In North America, the link between occupational exposure and breast cancer has been researched more systematically. With the epidemiology of occupational risks traditionally focused on cancers among men, a vicious circle has been established. A long-lived stereotype sees women less affected by occupational cancers. As a result, epidemiological studies of cancers often ignore female populations, and doctors tend not to ask questions about working conditions when diagnosing cancer in a woman. This systematic denial is boosted by occupational disease recognition systems under which it is very unlikely that a woman will manage to get her cancer recognised as being work-related. In North America in the 1970s, a protest movement developed among women with breast cancer, focusing on many aspects including the therapies, the dominating attitudes of male healthcare professionals towards women and their bodies, and the role of collective factors such as the massive production of carcinogens by industry. In the wake of this movement, the role of working conditions began to be explored. The research world only started posing relevant questions because this feminist movement had begun to influence the priorities of the scientific community.

A recent issue of the New Solutions journal provides an overview of the research undertaken between 2002 and 2017 in two complementary articles, one presenting a summary of the data from 142 publications, the other highlighting the need to transform the production of scientific research. One of the most widespread problems is that researchers rarely involve women workers when designing their projects: this was only the case in 3 of the 142 studies examined.

Though much work remains to be done, two findings are already evident: 1) we are now in a position to map specific occupational groups, showing the increased risks of breast cancer in certain jobs. 2) we already know a set of occupational exposures contributing to this situation: ionising radiation and chemicals found especially in solvents, pesticides, certain cosmetics, etc. In 2007, night shift work was identified by the International Agency for Research on Cancer as a probable carcinogen for humans (category 2A). Stress and long working hours are also suspected of increasing the risk of breast cancer. Moreover, the action of endocrine disruptors is not to be neglected.

There is a lot at stake. Accounting for more than 93,000 deaths in 2014, breast cancer is the primary cause of cancer mortality among women in the European Union, although very rare among men (around 1,000 deaths a year). In Europe, the number of new breast cancer cases diagnosed each year is rising, though mortality is on the decrease thanks to early detection and improved therapies. According to a study published last year by the European Trade Union Institute, effective elimination of the occupational factors could prevent at least 35,000 cases of breast cancer a year in Europe.

However, nearly all breast cancer campaigns continue to ignore the role played by working conditions.

Further reading


Image: © Martine Zunini
Black gold in Kosovo decides on its workers’ life and death

Kosovo, Europe’s youngest country, has the world’s fifth largest reserves of lignite, the cheapest and poorest quality coal and also considered to be the dirtiest fossil fuel. But has this been an asset or a curse for Kosovo? In thermal power plants Kosovo A and Kosovo B, salaries are generous but workers often fall ill and even die of respiratory diseases. However, in a country that has no established list of occupational diseases, little is being done to prevent this tragedy.

Barbara Matejčić
Freelance journalist

Photos by Atdhe Mulla
Out of a hot sunny day at the end of August 2018, Ismail Musliu enters the darkness of the ‘boiler’. This is what the new building of the Kosovo B power plant, where coal is fired, is called. And this is his workplace. Kosovo B provides heating for the capital city of Pristina, which is around ten kilometres away. It is half past one in the afternoon and he is taking a final tour of the boiler for the day. He needs to check once again that everything is alright. He passes by the coal mills and cauldrons in which the temperature reaches 500 degrees Celsius. Here and there sparks fly and thunder rumbles. The elevator takes him 61 metres high where he becomes wrapped in heat as the air temperature rises to 40 degrees. Dust sticks to his washed-out cotton T-shirt bearing the logo of the company that employs him: KEK, shorthand for the Kosovo Energy Company. Dust and tiny black particles of coal enter his eyes, nose and mouth. Ismail does not wear long sleeves, a mask, glasses or ear guards. He descends the metal grate stairs on foot. He does not hold onto the rail because, as he is not wearing gloves, it would make his palms completely black. On each level he peeks into the tubes, monitors whether there is any leakage, looks closely at the valves, checks whether something needs to be fixed. Indeed, it does: everything should be renovated because the machinery has been in use as long as Ismail has been working for KEK – 35 years.

Ismail is an engineering technician born in 1954. He is now less than a year away from retiring from KEK, the biggest state-owned company in Kosovo. KEK consists of a surface coal mine and thermal power plants, Kosovo A and Kosovo B, which produce 98% of Kosovo’s energy. They use lignite, the poorest quality coal and therefore the cheapest. Kosovo is not only the youngest country in Europe but, with only 1.8 million inhabitants, also one of the smallest. Nevertheless, the country holds fifth place in the world’s lignite reserves, with 14 billion tonnes of ari i zi – black gold, as they call it.

“Is this a curse or a blessing for Kosovo?” Ismail wonders. For himself, when he looks back on his working life he feels content because it was spent in a company with handsome salaries and because he reached retirement in good health. In the third poorest European country, where the unemployment rate is 26.5% and life expectancy for men is 69 years, this is no small success.

At 3 p.m. the workers of KEK are picked up by buses that take them home. Ismail steps on board in a clean blue shirt and grey pants. There is no air conditioning in the bus so the driver keeps the doors open for the workers to cool down. Above the door a sign reads: “O Allah, please save me and all the workers entering the bus, riding it and leaving it”. The transport used to be company-owned, as were the food and health services, but these have all now been privatised, and are consequently more expensive and poorer quality. The buses are old, the food is getting worse and medical expenses depend on insurance companies.

The bus drives around the outskirts of Pristina. The road is lined by cornfields, unfinished family homes, car showrooms, gas stations and scattered litter. After a half-hour ride, Ismail gets off the bus and walks home to his house on the hill. The interior of the house, built in 1997, is painted a calming white. It is situated as far away from the power plant and its polluting fumes as possible. He and his family used to live closer but there the dust was everywhere. They could not hang their clothes out to dry outside. In wintertime the snow was muddy. In the morning they would wipe down their furniture but by night time a dark layer would have settled over it once again. Since they could not fight the dust they had to escape it. Ismail has four grown-up children and he would not like any of them to work for KEK. “I had no other choice, but this is a difficult and dangerous job,” he says. When he showers at home, dark water drips off of him. When he blows his nose, a black trace is left on his handkerchief. His spit is black. Particles several micrometres in diameter can easily enter the lower respiratory tract and settle on the walls of the bronchi. The smallest ones break through into the lungs. These cannot be taken out.

“We worry about our fathers’ fate befalling us.”
Kosovo A: the worst single point source of pollution in Europe

Four out of the five Musliu brothers have worked in KEK at some point. Of these, only three are left as one brother developed cancer and passed away four years ago at the age of 62. His house is behind Ismail’s. In 2003 this brother was seriously injured at work. Having to climb quite high to tend to something around a pipe, he was hit by a rotating wire cable and fell on his head. He had to undergo two brain surgeries. KEK refused to pay damages or medical expenses so he sued the company and won 9,000 euros. He was on sick leave for months but was paid his salary for just one month. At the time, Ismail helped his brother and his family out financially, also helping to pay for his chemotherapy when he fell ill. Ismail is convinced that his brother’s illness was brought about by his work. Many of his colleagues died of cancer several years before their retirement, and many die after they retire. Workers in power plants or in the mine have no reduced years of employment and retire only when they turn 65, the same age as those working in offices. Men have the same retirement age as women.

The Kosovo A power plant has been declared by the World Bank to be the worst single point source of pollution in Europe. It was opened in 1962 and according to the government’s energy plan was supposed to be closed in 2017 and replaced by the privately owned New Kosovo power plant, which is financially supported by the World Bank. Plans to shut down Kosovo A and open the New Kosovo plant have been postponed to 2025 but construction work has not even begun yet, and it does not seem that anyone apart from the government or the KEK management believe this deadline to be realistic.

In its 2016 report, the European not-for-profit organisation the Health and Environment Alliance (HEAL) states that coal power plants emit thousands of tonnes of air-polluting particles which cost between 144 and 352 million euros in medical expenses. The worst effect on health is caused by high concentrations of the suspended particle PM2.5. Kosovo A and B emit the highest amounts of PM2.5 particles in Europe, with emissions as much as four times higher than those of most coal power plants in the Balkans. It has also been estimated that air pollution annually causes 852 premature deaths, 318 new cases of chronic bronchitis, 605 hospitalisations and 11,900 emergency medical examinations. It is not known how many KEK workers have fallen ill over the decades since no statistics have been kept.

Workers without medical insurance

This is what life is like in Kosovo. Until 2013 workers had no medical insurance nor were they paid compensation for work-related injuries. If they got ill they would not receive paid sick leave and they would have to cover their own medical expenses. “You get cancer and the union brings you five kilos of sugar, a kilo of coffee and that’s all. You turn into a welfare case,” recounts Rafet Osmani, the president of the new trade union in KEK. Even if deaths occurred due to accidents at work, the company would not pay anything. As a kind of compensation it was customary to employ a member of the family of the deceased. Today, if a worker dies at work, the family receives 25,000 euros. In case of an accident at work, 70% of the salary is paid during the 190 days of sick leave. If someone falls ill, only 21 days of their sick leave is paid for, although there is a chance of receiving 40% of their salary for a longer period of time if it is covered by their health insurance. In Kosovo, no list of occupational diseases exists, so it is impossible to establish whether an illness was caused by exposure at the workplace. Every death is considered to be a death by natural causes and not occupation-related.

However, there is no place for doubt when it comes to KEK; too many of their workers die of respiratory tract illnesses. Lung cancer. Throat cancer. Oesophageal cancer. “About 70% of workers live to reach their retirement. The rest die before they turn 65. And most of them live just another year in retirement,” says Osmani.

Along with health hazards – exposure to gases, dust, machinery vibrations and noise – the main problem at KEK is the small size of the workforce. “The age of our workers and of the machinery, that’s our problem,” says Osmani. The union estimates that in total there are 4,225 workers employed but that every year 150 to 300 workers retire. The average age of a KEK worker is 57. The union believes there to be a deficit of as many as 1,000 workers. “However, the government
won’t allow for new employment although KEK is the most profitable company in the country,” says Osmani, who is also a workplace inspector in KEK. "Many in the management of KEK either have their own private companies or have connections with owners of private companies. Instead of employing new workers, KEK outsources jobs to these private companies. Due to the shortage of workers in KEK, the existing ones are expected to cover several positions at once. This hinders the implementation of safety measures at work since not all of them have received adequate training for various positions."

**A drastic decrease in work-related injuries**

Our conversation is taking place in the building of the Institute for Occupational Medicine, the construction of which was funded by KEK and which used to belong to the company. This is where workers would come for their regular medical check-ups until the institute was privatised, at which point a fee started to be charged. With its hallways emptied of patients, doctors and nurses are idling their time away in front of the entrance, waiting for their shift to end. "We used to have fifty patients a day, coming in for their general medical examinations. They were not allowed to return to work without written verification that they had had their check-up," says Rexhep Kaquri, MD, Director of the Institute. "We also used to make suggestions about whether someone should change their position at work due to health concerns or when someone needed to pay special attention to a particular issue. We even had 24-hour duty. Should something happen to any of the workers we could intervene immediately. Now there is next to no one here because we are no longer a part of KEK, although we are the only occupational medicine specialists available. Our night shifts have been cancelled for the past two years because KEK stopped paying us. Almost three months ago our contract to do regular medical examinations expired and it still hasn’t been renewed. Not with us or with anyone else, although it is prescribed by law that workers undergo these examinations."

Still, the situation has improved a little. "In 2004, 380 work-related injuries were
recorded in KEK,” says Bekim Sadiku, an expert from the Office for Work Safety, Fire Prevention and Health Protection in KEK. “In 2007 there were 386, and in 2011 only 39. Finally, in 2017 just 7 injuries occurred. From 1999 until 2007 there were 43 work-related injuries with fatal outcomes. Nowadays, deaths hardly ever occur. The number of work-related injuries decreased because we started a more intense implementation of occupational safety and health training, which in 2011 became obligatory. Also, the supply of protective clothing has improved and internal controls of occupational health and safety tightened.” However, when it comes to falling ill, says Sadiku, there are no risk estimations for particular positions, and no one is responsible for doing this.

“Were Kosovo a member of the European Union we would have to close down both power plants. Limitations on dust emissions according to EU standards are 50 mg and here they sometimes reach as high as 200 mg. In fact they used to reach 2000 mg,” says Sadiku. Dust emissions have decreased at power plant Kosovo A due to filters installed on the chimneys in 2013. Furthermore, coal dust now gets transported by the hydro system, while before it was transported in open carriages which is why it got dispersed into the air.

A change of environment

Particles of coal dust inhaled in childhood can provoke later illnesses in adulthood. Fatmir and Fitim Mexhuani have been surrounded by dust their whole life, although both of them tried to escape it. They grew up in the house overlooking Kosovo A. The old power plant was their first neighbour. Fatmir says he was ashamed of visiting Pristina as a child. The soles of his shoes were always black and in the capital they called him “dusty boy”. Fatmir and Fitim are relatives, sons of two out of five brothers who were all employed in KEK. Four of them died in their fifties, their fathers among them. One died of gas poisoning and the others of cancer. “Our family covered their medical expenses,” say the brothers. Around fifty members of their extended family lived in this area. Today there is no one left; everyone went away due to pollution and dust, they say. We came across them when, after their workday in KEK, they came to visit the rundown, abandoned house with its garden of apple trees. Fitim, 45, was the last one to move away, a year and a half ago. Fatmir, 57, has lived in Pristina for a long time. We ask what it is like for them to work in KEK. A long silence ensues, punctuated only by the sound of the cocks crowing outside. Slowly they shrug their shoulders in response. Are they worried about their health? “Yes, of course. We worry about our fathers’ fate befalling us,” both of them reply without hesitation. “KEK pays zero attention to our health,” adds Fitim. He doesn’t seem particularly angry about it though; it’s as if both of them have surrendered to their destiny. They already left their homes to move away. They cannot leave their jobs as well.

As a kind of compensation it was customary to employ a member of the family of the deceased.
other workers we talked to. When he used to work in the mine he would need weeks just to clean his nose of dust. Ten years ago, when the new department was being set up, he applied for transfer straight away. It cost him 200 euros a month due to a smaller salary but he didn’t care. He knew that good health is worth much more. He grew up and still lives in Krushevac, a village in the vicinity of the power plant. For decades, the ash from KEK was dumped near his house, leading to the creation of Kodra e Hirit (translated as ‘ash hill’), as the locals have dubbed it, where there used to be plains. Ash would fly around and further pollute the already polluted environment. Today, however, Kodra e Hirit has finally been restored and turned into a green area. This is what Esat is working on.

A day earlier, in the KEK head office in Pristina, the company’s acting manager Njazi Thaqi had replied to our question about the increasing number of workers suffering from cancer by saying that cancer is common everywhere in Kosovo and that he does not attribute it to KEK but to the bombing of the country during the war. Many people in Kosovo believe cancerous illnesses to be in good part a consequence of NATO’s air force bombing in 1999 when depleted uranium was used. We ask Esat about his feelings on this matter. He gets upset right away. “That is not true. I know that there is cancer everywhere, but there is more of it here,” he says. “Last year two of my colleagues died of cancer in their fifties. My father is dying of throat cancer. He also firmly believes that it was brought about by KEK, because he lives nearby and because he worked in KEK for 40 years and there was no history of cancer in the family. My paternal uncle died of cancer, and he also worked in KEK. In my village there are only around twenty inhabited houses, yet around fifty people have cancer. Many of them work in KEK, especially the older generations, but others live nearby which boils down to the same thing. Only when I go somewhere far away can I smell the clean air. How then can all of it be from the war?”

His brother, Sherif Selimi, 41, who has also spent all his life in Krushevac, would like to find work in KEK. He expected to get employment there when his father, a worker at the company, got cancer. This used to be common practice, but it is no longer the case. Meanwhile, his wife Valbona, 40, has breast and skin cancer. Their son was diagnosed with bronchitis at the age of two. They are both convinced that it is all due to pollution: “the air we breathe, the land that gives us food, and the water we drink are all polluted.” Sherif shows us footage of Kosovo A on his phone. Despite the installation of filters, the smoke exiting the chimney is dark. “On weekends they turn the filters off to cut down expenses. You see how black this smoke is? That is why. And there is more dust and the smell worsens as well. It’s a disaster! A disaster!” KEK management say filters are turned on continually and that it is not as easy to turn them off without entirely shutting down production but Sherif is not so easily persuaded. It would take his family less than two hours to pack up and leave this place where they were born if they had somewhere else to go. But there is no such place. For Sherif, there is only one conclusion: “since we cannot move away, employment in KEK is the best option we have. It is killing us, but we depend on it.”
A couple alone against cancer

In Dottignies, a village a few kilometres away from Mouscron on the Belgian-French border, a man has been fighting for several months to get his partner’s cancer recognised as having been caused by her work. Working for a company in the textile sector, she was exposed to a carcinogenic solvent for fifteen years.

Denis Grégoire
ETUI
More than a year after receiving the diagnosis, speaking about her illness remains difficult for the 40-year-old worker. "Multiple myeloma" ... up to her appointment with the doctor on 27 November 2016, Laurence Petit has never even heard of the two words. Neither had her partner, Christophe Maresceaux. Indeed, multiple myeloma is a relatively rare form of cancer, affecting the bone marrow.

They hadn’t seen it coming. They found out quite by chance. Suffering from persistent fatigue, Ms Petit had been to see her GP. The blood test revealed anomalies: a "monoclonal peak", to use the exact medical jargon. The disease was detected at an early stage. With the cancer considered to be "dormant", the doctors did not prescribe any drastic medical treatment for the moment.

But what is it like living under the Damocles sword of a disease that attacks the bones? 'In ten years’ time, will I still be able to get around without assistance?', Laurence wonders.

"How can my partner have developed a cancer at the young age of 48?", Christophe wonders in turn. The question plagues this robust, affable and voluble man, not one to be satisfied with ready-made answers.

"The doctors are all focused on curing diseases. But when you ask then about the causes, they quickly give you the feeling that they’re not interested in this, that they don’t want to be disturbed."

Getting no answers from the medical world on the possible occupational causes of the disease, he got out his computer and started searching the Internet for information, in all directions. He drilled down into the available documentation, visiting the websites of such international organisations as the IARC, the International Agency for Research on Cancer, an offshoot of the WHO. Building up his contacts, he knocked on many doors.

He soon discovered that multiple myeloma could be linked to exposure to solvents. He bombarded his wife with questions ...

"Were you exposed to solvents when you worked at that textile company?" Laurence first said ‘no’, but later remembered always dipping her brush into a colourless liquid to clean it.

Throughout the day, some twenty women were subjected to the stink of glue, trichlo ... and cigarettes.

**Trichlo and cigarette smoke**

The couple live in Dottignies, a village a few kilometres away from Mouscron on the Belgian-French border. The industrial city of Roubaix is close by. For the last two centuries, this whole region has been dominated by the textile industry. But this prosperity seems to be over. While Mouscron still had some thirty textile companies providing work for 4,000 people in 1990, that number had dropped to 1,300 by 2012.

Christophe and Laurence received me in their large living room-kitchen, a sunlit and tastefully decorated room. While drinking coffee around the immense work surface in the middle of the kitchen, I asked Laurence to tell me how she found herself in contact with trichloroethylene at work.

Laurence Petit was just 19 when she started work at Antrafa, via a temp agency. The company was located close to the family home and she belonged to a family with no academic ambitions. "The oldest of five children, I had to go out to work to help support my parents", she explained.

Renamed Majaty in 2010, Antrafa is an SME producing catalogues for large flooring producers in the region. The young woman worked at the start of the chain, applying glue to the large cardboard sheets with the help of a brush, then placing them onto a conveyor belt for her colleagues to affix the carpet samples. To prevent glue building up on her brush, she regularly dipped it into an old tin full of liquid.

Laurence spent 15 years, eight hours a day, repeating these movements without ever knowing what exactly was in that tin. "It was called trichlo, the name mentioned on the bottle from which the forewoman used to fill our pots, once a week", Laurence Petit vaguely remembered.

"She now blames herself, feeling almost guilty of having trusted her former employers", her partner said. "Trichlo" was trichloroethylene, a chlorinated compound derived from ethylene and long used as a solvent in many industries. Starting in the 1950s, it was used a lot for the manual removal of grease marks from textiles, for cleaning machines and other equipment which had come into contact with paint, glue, adhesives, rubber, plastics, etc.

Suspected of causing cancer in the 1970s, it was replaced by another chlorinated solvent, 1,1,1-trichloroethane. After the latter was banned in 1995, trichloroethylene reappeared on the market, though used a lot less.

In that same year, the substance was classified by the WHO as being probably carcinogenic to humans.

The news did not seem to have reached Mouscron, where Majaty was to continue to use the substance throughout the 1990s and 2000s. Apart from using it to clean brushes, the company also made small bottles of trichlo available to the women workers to clean off any dried glue from their hands before lunch, as there were no wash-basins on the shop floor. This ritual was repeated when they knocked off work at the end of the day. Once a year, trichloroethylene was also generously sprayed on the factory’s conveyor belts to clean them.

Laurence Petit has no good memory of her former workplace: a building without
windows, with just artificial lighting, cold in winter, suffocating in summer. And above all very dirty. When the founder of the company handed over the business to his three children in the early 1990s, the cleaners were dismissed. The rooms were to be cleaned by the workers when they had time on their hands – in other words, almost never.

Throughout the day, some twenty women were subjected to the stink of glue, trichlo... and cigarettes. “Keeping a permanent eye on us from his office, the boss smoked one cigarette after the other. It would therefore have been difficult for him to forbid his employees smoking. The smokers even smoked while working”, remembered Laurence Petit.

In 1995, the young worker became pregnant. The label on the pot of glue in which she dipped her brush clearly stated: “Do not inhale”. Up to now very discrete and not very vindictive, Laurence put her foot down this time, insisting that she be given another job, one less exposed to the small pots of “trichlo”.

Though transferred to another post, she remained working on the shop floor until shortly before her baby arrived.

Though her pregnancy went without problems, her baby’s weight was abnormally low. The older daughter of Ms Petit was to be constantly monitored by the paediatricians from the Brussels university hospital Saint Luc until she was ten. At that time, she never considered any link with her work environment. But now, following the diagnosis of her cancer and after becoming aware of how she was exposed to hazardous products, Laurence wonders whether her daughter’s growth problems might possibly be linked to the toxic air she inhaled during her first pregnancy.

They look daggers at you

“Nothing has changed since”, one of Ms Petit’s former colleagues (who prefers to remain anonymous) told me over the phone. “There are still no wash-basins on the shop floor. To wash your hands – with cold water – you have to go to the toilets or to the cafeteria where we take our lunch break, the only break we get.”

In the winter, the workers have to wear woolen scarves and gloves to keep warm because the heating system doesn’t work properly. The pace of work is still intense and relations with management remain terrible. “You can’t speak up. If you do so, they look daggers at you”, she reported. She also complained of intense pain in her legs and back, blaming it on the conveyor belt which was too low.

However, the company stopped using trichlo several years ago. “It got replaced by another product, but I don’t know what”, she said.

“You can’t go making difficulties, not at our age”, sighed the worker who, like most of her other colleagues, is in the 45-55 age bracket. This resignation is explained by the lack of realistic work alternatives for unskilled labour in a region in the throes of deindustrialisation. The complete absence of any union representation in the SME is also no help, making it difficult for these vulnerable employees to put in demands for better working conditions.

In this context, the Petit-Maresceaux couple seem quite alone in their fight. To file their claim for recognition of Laurence’s cancer as an occupational disease, they have sought the help of their union. “We can’t do anything at this stage. Come back when Fedris has rejected your claim”, they basically told her. Fedris, the Belgian public agency in charge of compensating workers suffering from a work-related disease, is indeed not known for its generosity.

Studies carried out on rodents exposed to trichloroethylene point to an increase in the incidence of tumours of the haematopoietic system (organs involved in the formation of blood cells, including bone marrow). But Fedris gives precedence to epidemiological studies. Unfortunately, these have only been able to establish a link between trichlo and cancer of the kidney.

In the event of their claim being rejected by Fedris, the ex-textile worker will be forced to appeal against the decision in court – a scenario which the couple as yet cannot really envisage. But unfortunately, this is the situation facing the vast majority of victims of work-related diseases in Belgium in the 21st century.

1. It accounted for less than 2% of all cancers in France in 2011 (source: Haute Autorité de Santé).
3. IARC Group 2A This classification was revised in October 2012, with trichloroethylene being reclassified as a proven carcinogen (Group 1) following various studies showing a link between it and cancer of the kidney.
4. See also the article in HesaMag No. 15: “Recognition of occupational cancers: Belgian families’ fight for justice”. Available at www.etui.org/Topics/Health-Safety-working-conditions/ HesaMag

Special report 16/31
Preventing occupational cancer starts with data

Australian researchers have developed an IT tool for evaluating the exposure to carcinogens in a large number of industries. Used to process responses to a survey of 5,000 workers on their occupational exposure to carcinogens, it delivered concerning results: two Australians out of five are exposed to at least one carcinogen at work.

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The Australian study showed that the jobs most exposed to carcinogens were those of farmers and drivers of various types of vehicles.

Image © Belga
Occupational cancer is complicated. There are many different chemical and physical exposures at work which can cause many different types of cancer. The exposures to these carcinogens occur in many different jobs and are associated with different tasks. For example, demolition workers who remove asbestos lagging can contract mesothelioma and lung cancer, workers in rubber factories can develop bladder cancer, and outdoor workers may suffer from repeated skin cancers.

These occupational cancers may occur many years, or even decades, after the relevant work exposure, so in order to prevent cancer in the future, we need to act now. We already know a lot about what chemical or physical exposures in the workplace result in cancer. In many cases, we also know how to reduce exposure to these carcinogens. However, despite all this knowledge, it is not difficult to find workers who are still exposed to known carcinogens, even in high income countries. For example: bricklayers who cut bricks without masks; and miners who work underground with high levels of diesel exhaust.

How should we address this gap between what we know should happen and what does happen in the real world? One barrier to action is the complexity of the situation with multiple carcinogens, in a huge range of different jobs and industries. It was difficult enough to reduce cigarette smoking, which is just one carcinogen – how can we address multiple carcinogens, in a huge range of different jobs and industries? We can’t do everything, so where should we act?

These were the questions we asked ourselves a number of years ago. We thought there should be some way to determine how many workers were exposed to carcinogens at work so we could really understand the national landscape of risk and provide evidence to policy makers on where the problems existed. We wanted to find out how many workers were exposed to occupational carcinogens and what control measures were (and weren’t) being used. In particular, we wanted to know whether some workers were doing jobs or tasks where high levels of exposures to carcinogens occurred. We also wanted to know whether exposure to carcinogens was more common in sub-groups of workers, such as rural workers, younger workers, or migrant workers.

Our approach

Our method is based on the expert assessment method which was pioneered by Professor Jack Siemiatycki in the 1980s. He argued that rather than asking people what chemicals they were exposed to at work, it was better to ask them what they did at work (their tasks), and then engage experts in occupational hygiene to review the answers and assign exposures to carcinogens. This method has been used successfully throughout the world, but trained experts are hard to find, expensive to employ, and take many months to review the thousands of jobs in each study.

In around 2008 we realized that if these questionnaires were written carefully, we could use newly developed computing methods to replace the experts. There have been lots of studies about the levels of exposure to carcinogens in various jobs. More pertinent, many of these studies identify the factors which determine how much exposure workers receive (the determinants of exposure). For example, they might find that the type of engine or the distance the worker is from idling vehicles makes a difference to the level of exposure to diesel engine exhaust. We decided that we could use the results from these studies to design questionnaires which clearly identified whether or not determinants of exposure were present. We could organize a set of questions about a particular process into a task module. For example, we could have a painting task module for questions about preparing surfaces for painting, painting, and cleaning equipment at the end of the job. Then we could construct job modules from the task modules. For example, a job module for painters might include the task modules for painting, cutting wood, gluing, and driving. In turn, the painting task module would also be asked in job modules such as those for construction workers, farmers and janitors. Where appropriate, we could also gather information about protective measures used (including ventilation, respiratory equipment, gloves, and other protective clothing).

Once we had done that, we could then develop rules which would assign whether workers were exposed to each carcinogen. For example, if a worker said he worked in a large warehouse, close to many idling diesel trucks, a rule would assign high level exposure to diesel engine exhaust; whereas if a worker drove a petrol-engine car on country roads only, a rule would assign no exposure to diesel engine exhaust. We could use experts and existing studies to develop these rules and therefore use the expertise of the world’s best occupational health researchers to create a system which assessed exposures transparently, reproducibly, and rapidly.

The computer application we developed is known as OccIDEAS, which stands for Occupational Interactive Database Exposure Assessment System. It can be used for all stages of the process of assigning exposure to workers, including presenting the right questions to workers depending on their previous answers, assessing the exposures automatically, and providing exposure data as downloadable files. OccIDEAS provides a practical and transparent way to assess exposure to carcinogens in large numbers of people in diverse occupations.

The Australian Workplace Exposures Study (AWES) – Cancer

We used OccIDEAS in a study which aimed to determine the number of workers in Australia who were exposed to carcinogens at work, what tasks were most commonly resulting in exposure to carcinogens, and what controls were being used.

We selected 38 agents which had been classified by the International Agency for Research on Cancer as either carcinogenic or probably carcinogenic to humans. They included combustion products (e.g. diesel engine exhaust), dusts (e.g. asbestos, silica, and wood dusts), metals (e.g. chromium, lead and nickel), radiation (e.g. ionizing and solar radiation), shiftwork, and other industrial chemicals (e.g. benzene, formaldehyde).

We obtained a list of landline and mobile phone numbers from a commercial company, and our interviewers called them to ask if they would be in our study. We selected people who were aged between 18 and 65 and currently in paid employment and obtained complete interviews from 4,993 people.

Workers were more likely to be exposed if they were male, were qualified tradespeople, or worked in regional areas.
We found that over half of all firefighters never or only sometimes used breathing apparatus with certain tasks.

The interviewers asked each participant for their age, gender, postcode of residence, country of birth, and education level. They then asked for their job title and the main tasks they did in that job. From this information, we determined which carcinogen the worker was exposed to and at what level (low, medium, or high). We multiplied the results by the number of people employed in different occupations according to the latest national Census. This provided us with an estimate of how many workers in Australia were likely to be exposed to each of the 38 carcinogens.

What we found and how it has been used

Of the nearly 5,000 participants, we found that 1,879 were exposed to at least one carcinogen at work. Unsurprisingly, workers were more likely to be exposed if they were male, were qualified tradespeople, or worked in regional areas. We multiplied the numbers to get an estimate for the whole Australian workforce, we found that 2,700,000 men and nearly 900,000 women were exposed to at least one carcinogen at work - this equates to 58% of the male working population and 21% of the female working population. Overall, 2 in every 5 workers were exposed to at least one carcinogen at work.

Jobs which commonly involved carcinogen exposure were farmers and drivers of various types of vehicles. Being in Australia, a lot of work was done outdoors, and solar radiation was the most common exposure. Almost a quarter of all workers were exposed to solar radiation. Diesel engine exhaust, second hand tobacco smoke, benzene, wood dust and silica were also common exposures.

This broad brush information has given us an overall picture of carcinogen exposure in the national workforce. Before our study, it wasn’t obvious that more exposure occurred in rural regions than urban centres. And we did not realize that so many workers were still exposed to second hand tobacco smoke, in a country with very strict anti-smoking regulations. When we looked at this more closely, we realized that much of this exposure came from outdoor lunch locations, or from smokers clustering around entrances to buildings. Regulations have recently changed in many states to prevent smoking near entrances, so we would expect this exposure to have now decreased.

We have also been able to dig down further into particular exposures. We found that the most common source of exposure to formaldehyde was not laboratory or chemical industry tasks, but occurred when people cut and sanded composite materials such as plywood and particle board. Most of these workers did not use tools with inbuilt dust collectors or wear masks. Another unexpected source of formaldehyde exposure was to firefighters who don’t use breathing apparatus during the clear up phase after fires.

We can also look in detail at particular jobs. For example, road transport workers were not only exposed to diesel exhaust and benzene from driving but many of them also maintained and cleaned their own vehicles, resulting in exposure to benzene and asbestos. Many also either carried sand or rubble or drove on unpaved roads with their windows down, resulting in exposure to silica. When we looked at farmers and farm workers we found that all of them were exposed to at least one carcinogen and most of them were in fact exposed to multiple carcinogens, including solar radiation, diesel exhaust and various solvents. Only about 2 in every 3 farmers were exposed to pesticides, and pesticides were only the sixth most common exposure. This suggests that health and safety initiatives in farmers should not simply concentrate on pesticides, but address a wide range of exposures.

Further, we can look at the control measures which were commonly used by workers. For example, we found that over half of all firefighters never or only sometimes used breathing apparatus with certain tasks. In terms of sun exposure, most workers used at least one form of sun protection, although less than 10% of workers used a hat, long-sleeved shirt, shade and sunscreen for more than half the time they were in the sun. This suggests that more attention should be paid to the appropriate use of controls.

SafeWork Australia, which provided funding for this study, has used the results to target in various resources. Results from the study have been used by other researchers in their studies, and have been used by trade unions in Australia and internationally to raise awareness of the importance of carcinogens at work.

In a follow-up study, we recruited migrant workers to answer the same questions and found differences in exposure to carcinogens between workers of different ethnicities as well as differences compared to Australian-born workers. We also found that some migrant groups had more exposure to carcinogens even when doing the same jobs as the Australian-born, and that exposures were more common among workers who chose to answer questions in their own language rather than in English. This has resulted in increased focus by migrant support organizations on conditions of work for migrant workers, particularly for those with less English fluency.

Further studies have examined occupational exposure to agents which cause asthma, and to noise and chemicals which cause hearing loss.

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Further reading


Hunting for carcinogens at work

In a hospital in the south of France, one oncologist has managed to mobilise his entire department and others around a project to support patients suffering from work-related cancers. By tracking their occupational exposure to carcinogens, the project helps them to get their illness recognised as an occupational illness and raises the profile of a risk that is often under-estimated in a region of France that is one of biggest users of pesticides.

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Here in the department of Vaucluse, orchards extend as far as the eye can see into the distance that separates the villages of Le Thor and Caumont-sur-Durance. Avignon stands some 20 or so miles to the east. This fertile plain is one of the major fruit-growing areas of France, especially noted for its apples. At the end of August, seasonal workers can be seen packing cardboard crates with gleaming Granny Smiths that have just been picked.

Marc Maillan now observes the goings-on in the warehouses adjoining the imposing house he shares with his partner, Geneviève, with some detachment. The farmer handed over the business to his nephew a few years ago. From the age of 17 to 71, this great man’s daily life was devoted to growing apples, pears and, to a lesser extent, plums.

A family tragedy was to shape his destiny. While still a student at the local agricultural high school, his father suffered an accident while repairing a tractor and died. Along with his sister, he thus inherited a small plot of some 20 hectares.

This region is one of France’s most significant orchards, and most farms remain small-scale operations having, at least to some degree, avoided the stranglehold of the large agroindustrial groups. Not the stranglehold of the agrochemical industry, though, which has deep roots and a long history in the region.

“My grandfather would use lead arsenate to treat the trees,” recalls the retired arboriculturist. “Those products have always formed part of our daily life. During the mid-1980s, the large commercial companies that used to come regularly to visit us, Bayer and DuPont, began to advise us to wear masks and suits, and they encouraged us to invest in tractors with a cabin. Then some time later, the extremely volatile powders that we had to mix with water were gradually replaced with liquid products. We weren’t particularly concerned by any of this, however.”

And yet the septuagenarian clearly recalls the yellow and white oils that he used over long periods of time. He recollects his dog, who would follow the tractor as it was spreading the products, covered in a yellow film that would impregnate his coat for two months. He still smiles, although the general feeling is no longer light-hearted.

Farmer chemists

In 2015, after he had been feeling intensely tired for several months and had suffered severe weight loss – nearly 20 kilos in just a year – the axe fell: Vazquez disease. This is a myeloproliferative disorder, a malfunctioning of the bone marrow that disrupts the mechanisms for producing blood cells. “His platelet count had already fallen to 58 000, when previously it was over a million,” explains Geneviève, as she and her partner flick through the treatment guides that the pesticide companies send each year.

The 1998 “vintage” is a challenging manual for any budding chemist: DNOC or 4,6-dinitro-ortho-cresol (the active ingredient in yellow oils, banned in the European Union since 1999 due to its extreme toxicity); parathion (potentially carcinogenic to humans, according to the World Health Organisation); endosulfan (a reprotoxin) and so on. The guide recommends a total of 20 applications on apple trees between 10 March and mid-September each year. Not to mention the treatments recommended for pear, plum and other fruit trees. Marc Maillan’s occupation has also allowed us to create links with health insurance funds and even lawyers in legal firms, and with different partners that we didn’t know, like those involved in Giscop 93 in Paris and other local actors.”

Conversation with Christelle Besse, health executive in the Avignon Hospital Centre’s oncology/hematology department.

"The survey enabled them to talk about something other than their illness."

(Rémy Ponge, sociologist)
a north-eastern suburb of Paris. The recent transfer of the Parisian project to the south of France is the result of a slow process that started at the end of the 2000s in an oncology/haematology department in the Henri Duffaut Hospital in Avignon.

"We had been thinking about it in the department for 10 years when we started to note a convergence of two elements: on the one hand, increased ‘recruitment’ of patients and, on the other, an observation — shared with anatomical pathologists and biologists — that we were facing ever more complex cases and more developed diseases. It was on the basis of these observations that we realised we had to research other exogenous factors," explains departmental head Dr Borhane Slama.

The slender 40-year-old is the lynchpin of the project. His interest in the occupational causes of illness date back a long time. He has been collecting data on where patients work and live since 2008. "But the mere feeling that there is a problem is not enough, hence the need to design a scientific mechanism," states the oncologist from his modest office in Avignon Hospital Centre.

An extended survey of where people live and work

With the help of labour sociologists, the "Giscop" approach consists of piecing together the professional background of patients diagnosed with non-Hodgkin’s lymphoma in the most detailed and exhaustive way possible. In addition to this professional component, and unlike Giscop 93, the survey also comprises a "residential" component, enabling information to be collected on the successive homes occupied by the patient, particularly on whether they are close to different industries, nuclear facilities, treated farmland, etc.

Despite the shock of the diagnosis, the vast majority of patients agree to participate in the survey. "They are generally keen to obtain information and to provide feedback on a possible link between their professional activity and their illness. At the same time, however, they have a strong attachment to a career that has enabled them to build an identity and ensure their financial security, and this can complicate matters when it comes to admitting that they have been exposed to harmful products," notes Rémy Ponge, one of the three sociologists involved in the project. "The survey enables them to talk about other things apart from their illness," he adds, to explain the patients’ strong take-up of the approach.

An anonymised report is sent by the researcher to a team of experts drawn from

Recognising multiple exposure

The case of Marc Maillan is not really typical of the cases examined by Giscop 84. The quick recognition of the arboriculturist’s occupational disease and his speedy compensation are mainly due to the facts that his type of cancer is listed in one of the tables of occupational diseases in agriculture, that his disease developed while he was still working and that he was exposed to pesticides throughout his career.

Other agricultural workers monitored by Giscop 84 have seen their claims dismissed because too much time has passed between their stopping work and their diagnosis. In the case of non-Hodgkin’s lymphoma, the diagnosis must be made within a period of 10 years between the end of the work exposing the person to pesticides and the reporting of the disease. However, this principle does not take account of the particular nature of the agricultural environment. "It is very common for a farmer to continue to be exposed after retirement because he keeps lending a hand to his successors," explains Moritz Hunsmann, a CNRS researcher and coordinator of the Giscop 84 project. The farmer must also prove that he was exposed for at least 10 years.

While it was perhaps to be expected that traditional farmers would be over-represented, the Giscop 84 researchers are discovering highly fragmented career paths. "They may have started out in agriculture, but then switched to the construction industry, followed by the agri-food industry. These people have been exposed to a huge variety of carcinogens over a succession of different work periods, sometimes including illegal work," says Moritz Hunsmann. Exposure to carcinogens as a result of handling cleaning and maintenance products is another "black hole" that makes it particularly difficult to shed light on and, even more so, obtain recognition for carcinogen exposures.

The researcher considers that the French table system, which is the result of a “socioeconomic compromise”, does not take sufficient account of the multiple exposure to carcinogens.

This system facilitates the recognition of some specific work-related cancers by reversing the burden of proof: the worker does not have to demonstrate that his disease results from his exposure to carcinogens at work. This is the case, for example, for workers suffering from mesothelioma, an asbestos-related cancer.

However, it now seems clear that this “table system” relies on an obsolete monocausal scheme, i.e. the idea that behind an occupational cancer lies one single carcinogen. And yet, surveys — including the preliminary data delivered by Giscop 84 — have shown that a significant proportion of workers confronted with carcinogenic risks at the workplace are exposed to multiple carcinogens, in particular those whose career path has been characterised by structural precariousness (i.e. multiple temporary contracts in various sectors).
**Testimony**

"I wanted someone to recognise that my father’s health has been ruined by work"

The sometimes firm and sometimes quavering voice of Samira Belkhadir reveals the range of emotions that have filled her life since her father’s diagnosis with a blood disorder. Despite her exhausting two-year battle on behalf of this 70-year-old man, who is now very weak, the young woman from Marseille finally seems to be at ease.

“My father wanted to give up from the start. He said to me: I am tired, I am ill, I just don’t have the strength”, remembers Samira when she retracts all the steps taken between diagnosis and compensation of her father’s occupational cancer. “If you had not been there, I would never have done it”, he often says to me. “In all honesty, the compensation that my father received was not what it was all about. What we wanted was recognition of his status as a victim. I, and he too, really wanted someone to recognise that my father’s health has been ruined by work.”

Bouchaib Belkhadir worked for 25 years in an agricultural cooperative in L’Isle-sur-Sorgue, where he had several roles: initially he carried out handling work, but then, after gaining his HGV licence, he would deliver the fruit and vegetables grown on the highly fertile plain of the Sorgues. These tasks brought him into contact with numerous pesticides and other toxic products. “He used to immerse crates of apples in preservatives and then put them in a refrigerator, inside which a gas was sprayed over the stored fruit. The door of this refrigerator had a sticker with a skull logo on it”, recalls Samira. Before becoming employed in agriculture, Mr Belkhadir had, in the early years following his departure from Morocco for France at the age of 20, carried out gardening work for private customers, interspersed with apple- and cherry-picking. He also worked on a farm where he would plough the land, and sow and treat the plants.

“When he got the recorded delivery letter in January, I cried. I could finally say to him: Dad, you fell ill because you worked so much in your life”, the 30-year-old remembers, still very emotional.

As often happens in the cases that result in recognition of an occupational disease, there is a wife or children among the patient’s family, and sometimes even friends, who have taken on the extremely laborious administrative tasks required by the procedure.

“I ended up asking myself: Are they trying to discourage us or what? You have to go hunting in a past that dates back 20 years. I accept that an investigation needs to be carried out to check that a disease is in line with this principle, but why demand so much?”, the young secretary protests. “For people who are alone or elderly or who have no support, fortunately there is this scheme within Avignon Hospital”, she concludes.

"After maybe 60 years of married life, wives sometimes lose their husbands in just a few months. In these cases, the procedure for recognising an occupational disease extends the relationship."

(Eglantine Armand, social assistant)

"..."
Cancer in the hospital: one nurse’s lonely battle to defend her rights

Faced with two institutions largely averse to self-criticism, the medical sector and the justice system, one Spanish nurse stood her ground: her long battle for recognition of the occupational nature of the cancer that affected her almost 20 years ago has finally been won. She has taken this opportunity to highlight the risks other nurses face from the cancer treatments they administer.

Berta Chulvi
Journalist with the Spanish union confederation Comisiones Obreros (CCOO) and the Trade Union Institute of Work, Environment and Health (ISTAS)

Georgina fought for many years for legal recognition that her cancer was the result of her job as a nurse.

Images: © Tania Castro (p. 33, 35)
Georgina Angusto Zambrano does not find it easy to talk about a period of her life when, professionally-speaking, she was at her lowest ebb. But she is a woman that sees things through to the end. “I have just refused to tell my story to a Spanish newspaper because I have no desire to open up old wounds,” she explains as we sit down to talk near Cabre-rà, the suburban district of Barcelona where Georgina spends her summers and from where she first embarked, in August 1967, on a career as a nurse working in the urology clinic of a Barcelona hospital outpatient department. She was 17 years old at the time, and could never have imagined that she was to become ill as a result of preparing other people’s medication.

Georgina recently recounted her experience to the European Parliament because Rosa María Orriols Ramos, a member of the World Health Organisation’s International Commission on Occupational Health had, quite by chance, heard of her case. She agreed to go along, with her lawyer from the national risk prevention department nor any information from the hospital’s occupational risk prevention department nor any warnings from the doctors prescribing the drugs. No occupational risk assessment took place despite it being required by law.

Although she had a list of recommendations to give to patients, Georgina never felt they were running any risk because she had full confidence in her hospital’s medical team: “Patients were asked to urinate in different toilets to those used by their other family members, to flush twice and then to put a litre of bleach down the toilet bowl but at no time did we imagine that we were in danger. We didn’t have the least idea of what we were handling,” she explains.

She handled these cytostatic drugs on a daily basis for years, drugs that are all designed to interrupt certain phases of the cell structure. This property justifies their use in treating illnesses such as cancer, where the cells multiply in an uncontrolled manner. The process for preparing cytostatic medications is usually conducted in hospital pharmacies. A commercially produced product is processed as necessary (reconstituted, mixed, diluted, etc.) to obtain a drug appropriate for administration to the patient. Occupational exposure to cytostatic drugs can take the form of immediate localised effects caused by accidental exposure or long-term consequences caused by continuous exposure to patients suffering from bladder cancer.

From the year 2000, when her illness was diagnosed, until 2005, when the Catalan Supreme Court of Justice acknowledged that her bladder cancer was related to her handling of cytostatic drugs, Georgina fought a lonely battle. And, throughout it all, from becoming aware of the occupational origin of her illness through to the search for scientific proof, she fought it without any institutional support whatsoever. With an iron will, Georgina immersed herself in the medical literature for five long years, thus enabling her lawyer to organise her defence on the basis of scientific evidence that she painstakingly put together.

Georgina’s story illustrates the bitter failure of a system that neither informs its workers nor protects them from occupational risks. Her case is all the more serious because it occurred in a professional environment that should have known and been following preventive measures that would have enabled her to avoid this illness.

**I’ll show you how to do it**

During the summer of 1967, when Georgina first arrived in the urology department to replace a staff member who was leaving to have a baby, her colleague explained to her how to prepare the drugs to be administered

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1. Ley de Prevención de Riesgos Laborales, in force in Spain since 1995.
low-dose exposure. Cytostatic drugs are recognised as being mutagenic, reprotoxic and carcinogenic, and they are associated with cancer of the bladder, carcinoma of the nasopharynx and leukaemia. They can also result in miscarriages and birth defects.

The first sign

The first sign that something was not right in the urology department came from another nurse. "When a colleague showed me his blood-streaked urine, I guessed it had to be a tumour as there was none of the pain you would associate with colic. This nurse also knew deep down, but did not want to admit to the evidence. He underwent bladder bypass surgery," the nurse recounts of her colleague, 12 years her senior and suffering from stage 4 cancer of the bladder. A year later, Georgina discovered blood in her urine. The diagnosis was the same. A tumour in the bladder. When she told her colleagues of her symptoms, they all said, "Surely not! There are plenty of other things it could be." The ultrasound, however, very soon confirmed the presence of a tumour. "They made me wait more than an hour in the ultrasound room, which only confirmed my suspicions and, when they arrived, they told me, 'Well, it's not serious. It is a bladder tumour but only a tiny one. We'll remove it next week and that will be that.'"

When Georgina came across her sick colleague in the department, she very nearly exclaimed, "You've contaminated me," but quickly thought better of it. "That's when I realised that cancer isn't contagious," recalls the nurse. This awareness was like a sledgehammer blow for someone who, like Georgina, loved her job with all her heart and who had devoted herself body and soul to her work. No time to linger over such considerations then; she had to defeat her illness. "The doctors were worried and took some exploratory bone samples as they were concerned they might find metastases in the bone. The examination showed nothing but I had to remain in bed on anti-inflammatories," she explains. Following a meeting with her oncologist, Georgina contacted the library at Barcelona Medical School to request the technical instructions for all the drugs she had ever administered over the years. What she learned left her in shock. "These drugs were extremely dangerous and we had been administering them without following any of the precautions advised in the instructions."

Scientific proof and the legal battle

Georgina then went to the Catalan Government's occupational risk department to find a 1976 document that gave a whole series of recommendations for handling hazardous drugs, which, in her case, had not been followed. This document was based on another from the World Health Organisation from 1975. She contacted a firm of lawyers immediately. Ana Salas shared her client's intuition as to the occupational nature of her disease. Cytostatic drugs are recognised as being mutagenic, reprotoxic and carcinogenic, and they are associated with cancer of the bladder, carcinoma of the nasopharynx and leukaemia. They can also result in miscarriages and birth defects. This awareness was like a sledgehammer blow for someone who, like Georgina, loved her job with all her heart and who had devoted herself body and soul to her work. No time to linger over such considerations then; she had to defeat her illness. "The doctors were worried and took some exploratory bone samples as they were concerned they might find metastases in the bone. The examination showed nothing but I had to remain in bed on anti-inflammatories," she explains. Following a meeting with her oncologist, Georgina contacted the library at Barcelona Medical School to request the technical instructions for all the drugs she had ever administered over the years. What she learned left her in shock. "These drugs were extremely dangerous and we had been administering them without following any of the precautions advised in the instructions."

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illness. Suspicion is one thing, but scientific evidence is another.

The nurse began to undertake exhaustive bibliographic research in reference medical publications such as *The Lancet*, the *Journal of the National Cancer Institute* and the *Journal of Urology*. “Each reference sent me to additional documentation. I studied mountains and mountains of articles, most of them in English and a good number of which I had to translate with the help of a childhood friend or by calling on the paid services of the Escuela Oficial de Idiomas (Official Language School). It became clear that research highlighting the dangers of cytostatic drugs had been published since the 1980s. The obvious question was: ‘Had no one at the hospital read these articles?’.”

There was plenty of information on cytostatic drugs but her lawyer did not feel that any of it was conclusive. It would take more than this to discourage the nurse and so she threw herself into her research with even more determination. And then one day she found the crucial element: a study published in July 1993 in the *Journal of the National Cancer Institute*. It described the case of a 39-year-old pharmacist who had been handling cytostatic drugs for more than 10 years, especially one of those administered by Georgina, and who had developed a tumour of the bladder despite presenting no other risk factors. The researchers showed that the cabinet in which the pharmacist had been handling the drugs had been equipped with a horizontal laminar flow extraction system rather than a vertical one, so that the fumes drifted out towards the pharmacist’s body and into the room in which they were working. “And we were preparing these mixtures without any cabinet at all!” says a still shocked Georgina.

On the basis of these documents, Ana Salas drew up an entire action strategy prior to going through the courts: first, they submitted a complaint to the Spanish Health and Social Security Inspectorate, and provided the evidence relating to the handling of cytostatic drugs and resulting health risks. Once the Inspectorate had acknowledged the occupational nature of the illness, Georgina then went to the Toxicology Department of Barcelona University to undergo genetic tests to establish that the disease was not hereditary. Ms Salas and Georgina finally won the battle in the courts. Her cancer was recognised as an accident at work and she can now benefit from the social security provided for occupational illnesses.

Following this victory, the nurse embarked on another no less complex journey: she was 50 years old and had to rebuild her life outside a job that not only provided her with an income but that also represented a crucial source of personal fulfilment for her.

“I’ve put all that behind me now, but I find it difficult to look back on it, even though the final battle was won. It still pains me to remember how powerless we were. I find it difficult to believe that no one in the hospital had read those scientific articles and even more difficult to understand their silence,” she concludes, her voice full of life, positive and kind, a tone used by those who know that – when the time came – they did the right thing.●
When illness puts work into a different perspective

Life expectancy is rising, as is the duration of working life, while new treatments are helping people work longer despite being ill. But there are still very few support schemes for helping people to get back to work or change their field of work. “Chronic illness and activity” support groups were an experiment, focusing on peer-to-peer exchanges and getting people out of their isolation.

Elsa Fayner
Freelance journalist

“Being part of this support group helps us to realise that we are not alone in these situations.”

Image: © Martine Zunini
"I didn’t feel well, I didn’t know to get out of the rut, how to get myself back on track." Now 65 years old, Nadine was diagnosed as having breast cancer in 2010. At the same time, the training centre she was in charge of – a centre for people in difficulties – had filed for bankruptcy. Nadine’s primary focus was initially on closing down the centre, while also starting the treatment. But once the administrative steps had been finished, her cancer started showing its ugly face and Nadine felt “very, very bad”: “I wasn’t old enough for retirement. I had cancer, had filed for bankruptcy, was out of form... I went from having lots of responsibilities and energy to having nothing at all, because I just wasn’t able to do anything.”

48-year-old Isabelle from Paris went through the same: “After having been off work for three months following the cancer diagnosis, I was able to go back, though only part-time. I found this to be the only way to cope with the fatigue and pain, while at the same time making some money and feeling of use to the company I worked for. But it put an abrupt stop to my career.”

Though her illness has since stabilised, she is no longer happy with her work, feeling that she has been “relegated” in her department, “blocked”. “I’m being given less interesting things to do. It’s not easy to keep hold of stimulating cases when you’re not there all of the time. Not working full-time is still not the accepted thing in France.” It was the doctor who had suggested to her to work part-time on health grounds. At the hospital, Isabelle also had a session with a psychologist on being informed of her diagnosis. “But that was just one-off support. I couldn’t really find anybody to speak with about working while ill”, she regretted. But what helped both Nadine and Isabelle was a flyer informing them of the existence of a club specifically for people like them, the “Club maladies chroniques et activité”. Located in the Cité des Métiers in Paris, the club offers people suffering from chronic illnesses, first and foremost cancer, support for a limited time in getting back to work.

Older workers, more likely to be ill

Italians take retirement at 65, Belgians and Germans at 67 (as of 2029-2030) and Britons born after 1970 at 68. Sweden has announced that it will be raising the official retirement age from 61 to 64. As a result, Swedes will be able to work until 69, against 67 at present. Throughout nearly all the European Union, men and women are going to have to work longer, well into their sixties. Yet, for the majority of cancers, the risk increases with age. Many forms of cancer rarely occur before the age of 50. According to the Belgian Foundation against Cancer, on average, 60% of cancer patients are older than 65. According to a large-scale survey conducted in France in 2016 by the French Institute for Public Health Surveillance (InVS) and the National Cancer Institute (INCa), the 5-year survival rate has improved over the last few years for the main forms of cancer. This basically means that more and more Europeans are likely to be ill while still working, creating completely new situations.

Cancer is one of the chronic diseases defined by the World Health Organization (WHO) as a “health problem requiring several years of care and often involving invalidity and the threat of serious complications”. While covering very diverse realities, these diseases have two things in common: their duration which no longer allows then to be seen as a brief interlude in the course of a lifetime, and an obligation to manage the chronicity in all spheres of social life. For those suffering from cancer, treatment is not a synonym for cure but for coping.

Chronic diseases differ from acute diseases in their duration, their alternating critical and stable phases, and the unpredictability of their evolution. Apart from phases of intensive treatment, they do not necessarily mean that paid work has to be suspended. Nevertheless, they do constitute a higher risk of occupational disability, of work limitations, of job loss or a change of job, of absences from work. Little visible or even unutterable in many cases, the consequences of chronic disease are often underestimated, denied or not properly understood, and hardly at all debated in the world of work. However, as shown by several qualitative studies of sufferers of working age, the majority of them want to continue working or to return to work, not just on financial grounds or for the interesting work and the contact with colleagues, but also because work is a powerful instrument for escaping from the grip of the disease itself and from the imprisoning social status of being ill. How are these alternating treatment/work periods experienced? Is returning to work promoted or not? What support schemes are available? What can be learned from the “Club” referred to Nadine and Isabelle?

Very few schemes

After having filed for the bankruptcy of her training centre, Nadine registered with the Job Centre and, with the encouragement of her employment counsellor, requested a skills assessment. “Apart from the Job Centre quickly directing me to a service provider for the follow-up, and apart from the latter – at 1:30 on the bus from home – requesting me to do an internship and to write to as many employers as possible, there was no support at all”, remembered Nadine. “The requested skills assessment was swept under the carpet, God knows for what reason.” At that time, the 60-year-old felt too weak for a full-time internship and a fast-track return to work. She had no idea whom to contact, who could support her in finding new work while taking the time needed to look after herself and rest. It was the same story with Isabelle, whose company was similarly little able to cope with the situation. Her annual appraisal sessions did not lead to any improvements, despite her repeated requests. Since informing her company of her illness, Isabelle, who worked in marketing, had been entitled to no more than two days of training.

1. Forenames with an asterisk have been changed at the request of those concerned.
However, in France, a number of companies have signed the Cancer and Employment charter drafted by the INCa, undertaking "to retain staff suffering from the disease and to help them return to work". Some 1,200,000 employees are now covered by the charter. Some companies are even going further, calling on the help of Anact, the French national agency for the improvement of working conditions, to find ways of adapting the workplaces of sufferers to the constraints imposed by the diseases – unforeseen absences, treatment during working hours, bouts of fatigue, part-time work, etc. – rather than calling on the sufferer to adapt to the constraints of the workplace. But such cases remain the exception.

Outside of companies, the majority of schemes provide individual support within the context of medical/social or more specific psychological consultations. But the situation is changing, slowly but surely, with the role of collective approaches increasing. In many cases, these schemes are presented as "support groups", in which goals, behaviour and various reference situations can be discussed. We can thus distinguish between self-help/support groups which give priority to discussions between peers and are mainly to be found in the third sector; "therapeutic education" groups often set up in a hospital setting; and psychotherapeutic groups in different shapes and sizes, whether psychoanalytic, systemic, behavioural or other.

Clubs for speaking about illness and work

Within this movement, an experimental "research/action" programme was conducted between 2010 and 2013, aimed at looking into the link between work and chronic illness. Financed by the National Cancer Institute (INCa) and the Cancérople d'Île-de-France, the programme was implemented by a team of psychologists and sociologists working for CNAM, the National Conservatory of Arts and Crafts in Paris. The goal of the programme's "Clubs maladies chroniques et activité" is to better understand the obstacles in the way of letting a person return to work or retaining his/her work and to take action aimed at allowing a situation to develop in which work is done to the detriment neither of a sufferer's health nor of a company's business performance. To take part in such a Club, three conditions have to be fulfilled:

"Looking for a job is full-time work. (...) But when you’re ill, you’re tired and handle time differently."

the person concerned must be of age, have a chronic illness and wish to resume work. It soon turned out that cancer was the disease accounting for most of the cases

"I needed routine support in dealing with my colleagues and managers", reported Corinne, an employee in a stage of cancer remission. Like all participants, she had started by meeting the Club’s organisers, with a view to the latter finding out about her motives and explaining the approach. She then joined the group of working sufferers for 2.5-hour meetings once a fortnight. It quickly became necessary to distinguish between two groups: those with and those without a job. In both cases, at the start of any meeting, each participant gave a report on how things were going, to which the others could chip in: "That echoes my experience; ever thought of contacting a social worker?"; "Are you aware that Agefiph offers a disability allowance? That could help you pay for an Autolib to get to work?"; "You should go and see a lawyer. Your company has no right to do that!"; "Drop it. It’s not good for your health to be involved in a fight at the moment"; "In the sector I work in, that’s what I would do if I were you; "Try to figure out what you can still do when you get so tired"; etc.

"What makes the Club so effective are the collective discussions. And the fact that we all have different illnesses; this avoids us moaning or comparing drugs. There’s not so much chance of getting dragged down", thought Isabelle, the former marketing assistant. "Being a member of this group helps me realise that we are not alone in having to face up to such situations", affirmed Corinne. "And that we are not responsible for everything." A number of participants spoke of the vitriolic coming from managers and employers. "It’s very good to have this opportunity to speak outside a home setting, where we don’t have to go into detail", thought Corinne. "Peers don’t judge. As they’re all in the same boat, it makes discussions much more fruitful. They also don’t take pity on you, in contrast to certain friends who give advice."

What sometimes also helps is to highlight the paradoxes in participants’ expectations, or to help people also realise that they might be adopting attitudes at work that do not facilitate relationships or about which they would otherwise complain. Corinne, who found herself shuttling back and forth between her company and her treatment, had for example decided to stop going to the company canteen for lunch. Instead, she ate a salad sitting in front of her screen to avoid losing time. "Describing this to the group, I realised that I was contributing to my isolation." Changing her habits, she now finds herself better integrated in her new organisation, a smaller company than her previous one.

Putting work into perspective

Over and above information about whom to contact and useful schemes, on the right way to approach them and on ways to avoid being depressed in the face of the complex documentation to be submitted, the most frequent question relates to adapting to the new context, remarked Corinne, a jurist by training: "Participants realise that they cannot go on working the same way as always, that they have to adapt their work and their use of time to stay healthy. And that they have to change their lives."

"The question of the meaning of the work also arises, with work no longer just a means of earning your living. You now have to look for ways of giving your work a meaning. You have to decide what your role is to be in the world, despite the fact that you might possibly die quite soon. Group participants are less able to cope with working conditions and jobs not in line with their ethics, but also with meaningless tasks, rules, idiots, all that wasted time", recalled Nadine.

2. The association running the fund for integrating the disabled in the labour market.
3. An electric vehicle made available to Parisians via a car-sharing service. It ended on 1 August 2018.
Interview with Dominique Lhuillier, professor emeritus in occupational psychology at the National Conservatory of Arts and Crafts (CNAM) and with sociologist Anne-Marie Waser from the “Clubs maladies chroniques et activité”. The two are co-authors of the book *Que font les 10 millions de malades ? Vivre et travailler avec une maladie chronique* (Érès 2016).

Interviews by Elsa Fayner

What gave you the idea of working in groups on this topic linking work and chronic illness?

I had worked before on the relationship between work and the adaptations necessary for those suffering from Aids. Visiting associations of sufferers, many of which has set up support groups, I saw the benefits of such groups. But even then, as many of these groups focused on just one disease, I found the discussions often revolving around forms of treatment, and rarely around work, despite the fact that many of these people, due to the progress made in treating their diseases, wanted to work. At the same time, I had spent many years leading workgroups on occupational practices. On the basis of all these experiences, we set up our “Clubs maladies chroniques et activité”.

Work is not just paid work

Reducing work to paid employment cuts it off from other forms of human activities. However, there is no preset dividing line between all these activities and paid work. Being ill transforms this system of activities, obliging people to set priorities reflecting both their aspirations and desires – desires in many cases adapted by the experience of the illness and the awareness of the finite nature of life – and the constraints and available resources. An investigation of the various activities makes it possible to get your bearings, making the most of all the experience and know-how gained in different spheres. This is the reason why the results of this research/action programme cannot be just reduced to changes in employment situations. It has a wider scope, enabling participants to start the long process of transforming both their lives and their surroundings with a view to living in reasonably good health.

What does this “double transformation” involve?

The “we” aspect is undoubtedly a key aspect for those enduring a disease all alone: when you just haven’t got any chance to talk with others, you tend to lose touch with reality and to get overwhelmed by doubts. Am I becoming mad? Am I making up what I feel?

The group appears as a space where the sick person finally has the opportunity to speak about things that are taboo in the lives of supposedly “non-ill” people. These discussions enable sufferers to ‘de-privatise’ their experience of the illness at work, making it a subject around which to link up with others. They tend to invert the relationship with the illness, restoring the ability to act on it: we might then see expectations of help or support being replaced by efforts to transform one’s work and, going one step further, to transform work overall.

What limits have you come up across in the first few Club meetings?

We held some 50 meetings, at a rate of two a month. People were always coming and going, but on average six people usually attended a meeting. The majority (75%) were women between 21 and 60, half of whom were younger than 45, and 70% of them had upper secondary or tertiary education. This we see as a limitation: the social level of the participants was rather high.

The experiment has now finished. Will there be a sequel?

There already is a sequel! The City of Lille has contacted us, asking us to organise support groups focused on the conditions needed to keep people suffering from a chronic disease, an accident or a disability in work. This constitutes a new challenge, as the groups are organised within the regional authority.

Renunciations and commitments

Not having a job leads to further questions: should you tell a future employer about your illness, without knowing anything about the working environment in the company? Should you ask whether telework is possible, whether you had spent paid time in touch with your work? And did you ask for the redistribution of work? And did you ask for an extension of sick leave? And did you want to work. At the same time, I had spent many years leading workgroups on occupational practices. On the basis of all these experiences, we set up our “Clubs maladies chroniques et activité”.

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We held some 50 meetings, at a rate of two a month. People were always coming and going, but on average six people usually attended a meeting. The majority (75%) were women between 21 and 60, half of whom were younger than 45, and 70% of them had upper secondary or tertiary education. This we see as a limitation: the social level of the participants was rather high.

The experiment has now finished. Will there be a sequel?

There already is a sequel! The City of Lille has contacted us, asking us to organise support groups focused on the conditions needed to keep people suffering from a chronic disease, an accident or a disability in work. This constitutes a new challenge, as the groups are organised within the regional authority.
In East Ukraine, antiquated hospitals, with equipment ripe for a museum, serve an impoverished population

The Soviet health system was considered as being one of the best in the world. All that’s left of it in Ukraine are memories. The level of public health provision has dropped greatly over the last few years, and the hospitals are desperately under-resourced. In the east of the country, at war since 2014, healthcare staff are struggling to meet the growing needs of patients. A report.

Sébastien Gobert
Freelance journalist from the D&B collective

Photos by Sadak Souici - Agence Le Pictorium

Konstantin Zougan, urologist, surgeon and head of the Roubijnè city hospital.
Large black plastic sheeting taped to windows does not prevent daylight from seeping through. The gloomy glow of old yellowish bulbs is reflected on a faded tiled wall. A woman wearing a face-mask makes her way past the antiquated equipment, throwing a cloth dripping with blood onto the floor before taking her place at the operating table to assist the three surgeons, at work on an unconscious man. "It's an aorta operation", explained Konstantyn Zougan from the door. "The conditions aren't that ideal, but at least you're among our top specialists."

"And in this operating theatre, at least they're using one of our new operating lamps. In another room, we're still working with a model dating back to 1973..." Konstantyn Zougan, a urologist and head surgeon at the city hospital in Rubizhne, took his visitor on a tour of his operating theatres. "We've no decent sterilisation equipment and no air compressors. And we've only got one working defibrillator. As you can see, nothing has changed here since the 1970s-1980s, the Soviet era. Even the wheelchairs belong in a museum."

**An inexorable decline made worse by the war**

Speaking with Konstantyn Zougan, you notice a certain resignation in the face of the precariousness of his working conditions. Since Ukraine gained its independence in 1991, the country's health system has been hit by a political wait-and-see attitude, a severe lack of modernisation and endemic corruption. The situation became even more complicated in 2014, at the time of the first skirmishes between Ukrainian troops and pro-Russian separatists and Russian forces. After four years of a war with a death toll of more than 10,300 according to the UNO, Rubizhne is now just 60 kms away from the front line separating the oblast (region) of Luhansk. The skirmishes remain regular and deadly.

Despite all this, Konstantyn Zougan's operating theatres run 24 hours a day, 7 days a week. "We've got no choice", he remarked. There are more than 50,000 people living in Rubizhne, an industrial city. Ravished by a permanent economic depression and bruised by the conflict, the city is also the home of many thousands of displaced persons. The latter "have left everything behind them. They are living in precarious conditions, and not eating properly. They are subject to stress and all sorts of psychological complications", the surgeon went on. "The additional workload is substantial. But you can't turn people away."

The urologist takes comfort in the stability of his team and in the humanitarian aid which ensures regular supplies of drugs, medical equipment and which sometimes even allows the decaying infrastructure to be refurbished. Pride of place in the Rubizhne city hospital is taken by the second-floor maternity unit, completely refurbished in 2014. Reaching the top of a dusty staircase, we find ourselves in a sterile corridor painted with fresh colours. The doors have been widened to allow the modern hospital beds to get through. Each room has large windows and its own bathroom.

"It's even warm in the winter now"; enthused Svitlana Niskaradiva, a doctor who has been working in Rubizhne for 25 years. For the last 12 years, she has been in charge of the maternity unit, supervising a team of 12 midwives and 7 nurses. She clearly notices the difference. "The new-born babies get all the care they need", she explained, showing us the state-of-the-art incubators and test instruments. "The refurbishment has had a positive effect on the overall state of health, including that of the mothers. But also on the working conditions and on patient relations. The young mothers are less worried in such an environment, making it easier for us to assist them."

In Rubizhne and the surrounding area, this return to normal maternity standards is salutary, as "the overall level of public health has dropped in recent years", said Svitlana Niskaradiva. "You won't find any children here in the region without a health problem", she continued. This is due to the serious industrial pollution, the badly-insulated flats and schools, chronic malnutrition and the low vaccination rate. Some of the illnesses, such as diabetes mellitus, used to be treated in the regional capital, Luhansk, explained Svitlana Niskaradiva. "We needed to restructure many of our departments after the region was divided."

**Uncertainties**

Carrying on speaking, the doctor went down the stairs to the first floor, emerging into a dark corridor, the walls with the plaster coming off, the floors covered with scraps of PVC carpet tiles. A typical postcard picture of a post-Soviet hospital. On this floor, pregnant
women remain under observation until they give birth. "We jokingly motivate them: give birth and you can move up to the refurbished floor", laughed Svitlana Niskaradiva. On a more serious note, the doctor deplored the fact that the refurbishment of this ante-natal ward was not yet planned. "We are doing the maximum possible", said Christian Carrer, head of the AICM-Ukraine foundation, one of the most active humanitarian aid organisations in Rubizhne. "But needs are just immense, and Rubizhne is far from being the only hospital in the region in distress."

Letting the humanitarian organisations and local authorities get on with piecemeal modernisation projects, the central government is focusing on the impact of a general overhaul of the health system. Supported by Ulana Suprun, the American-Ukrainian Minister of Health in office since October 2017, the aim of this initiative is to develop an Anglo-Saxon way of running the system upon the ruins of the inefficient post-Soviet system. In the firing line is an overhaul of hospital financing, making it needs-based instead of size-dependent. Also on the agenda is the establishment of a social security and health insurance system, as well as a strengthening of a GP’s gateway role, with patients registered strictly according to their place of residence.

Planned to be rolled out by the end of 2020, the new system is supposed to give healthcare professionals and patients greater autonomy and flexibility and to make the whole system more efficient. It is also supposed to put an end to the habit of giving "gifts", sums of cash handed over by patients to the doctors to top up their meagre wages. Under the current system, junior doctors, like nurses, get a fixed wage of 3,200 hryvnias (about €104) for 24 days a month, 8 hours a day. This obviously encourages all sorts of corrupt practices. Henceforth, each GP will be given 370 hryvnias (or 12 euros) per year for each patient registered with him. "Patients will no longer need to hand over ‘gifts’, as doctors will now be well-paid. And healthcare professionals will be motivated to provide better care as a way of attracting new patients", explained Inna Boiko, head of the "Ukraine Patients" NGO.

However, Konstantyn Zougan in Rubizhne has his doubts. "This reform is set to greatly upset our – already very difficult – work. It is under-funded and takes little account of current structures. One of the first steps for instance involves registering patients, doctors and hospitals in the online e-health database. "But we haven't got either a computer or Internet", the urologist said derisively. He nevertheless remained hopeful: "As long as we can keep our team of professionals together, we'll be able to carry on helping our patients. That's the main thing."

Working in a forgotten corner of Ukraine

A solidarity not found everywhere. 140 kms to the south of Rubizhne, head doctor Valeriy Ivanov has to make do with just 50% of his doctors and 48% of his nursing staff at the Stanitsa Louhanska hospital. "It's a disaster", he said, slumped in an old office chair. "Nobody wants to come here to take the place of the missing professionals. And I can understand why... Just a few hundred metres away from the hospital, the Siverskyi Donets river marks the front line. On its other side, just fifteen kms down the road, lies Lahansk, capital of one of the self-proclaimed separatist republics. Under regular bombardment, prospects for the future are more than uncertain.

Isolated at the eastern end of Ukraine, between the front line and the Russian border, Stanitsa Lahanska remains the main hospital for the remaining population of 48,000, most of them pensioners. Numbers are swollen by some 15,000 displaced persons. "We treated more than 18,000 patients in the first three months of this year", said Valeriy Ivanov. However, of the three surgeons he had in 2014, just one is still there, and one out of two traumatologists has left. The radiologist comes from another raion (district), but only when he can manage it. "We can’t pay him to come here, as the law forbids doctors to draw salaries in different raions", added Valeriy Ivanov. As for the anaesthetist, he is a military doctor standing in for his civilian counterpart. At Stanitsa Louhanska, as with other front-line hospitals, the Ukrainian army has requisitioned a hospital wing.

Here as well, any modernisation of facilities takes place in a piecemeal manner. Valeriy Ivanov feels abandoned by the humanitarian organisations, other than the International Committee of the Red Cross or Doctors of the World which organise distributions of drugs. "The regional authorities have just given us a new X-ray system, replacing the two antiquated systems installed in 1983. But if a patient needs an MRI, we have to go elsewhere", i.e. to take a trip of at least 80 kms along pot-holed roads punctuated by military checkpoints. The hospital has two vehicles at its disposal, one of them a 1994 Toyota. «That one deserves a medal, as a tribute to its services! But at the moment, we’ve got to make do with it», said Valeriy Ivanov ironically.

Despite its highly sensitive situation, the hospital receives no preferential treatment from the State. Hit by shelling in 2014, the building but had to wait until the spring of 2018 for the repair work to be done. Its last complete refurbishment was in 1973. It would need 7 million hryvnias (about €229,000 euros) to get it back up to standard. "Nobody’s got that sort of money here", said Serhiy Ivanov with a sad note in his voice. His office with its plywood walls boasts neither air-conditioning nor computer. "I am well aware that the State gives priority to large regional centres. But that’s no reason to forget the people here, in this remote corner of the country."

Valeriy Ivanov and his team cannot forget their patients, for the most part pensioners, sleeping six to a room on antique spring base beds. In a small canteen upstairs, a team of nurses spoon their soup with a smile, patiently confirming that they’ll be staying on despite the war. "The staff we’ve got here now all went through a terrible spell in 2014-2015 which welded them together. They’ll never leave", said Valeriy Ivanov, whose family is now scattered between Lahansk and Kiev. "But what is more worrying is the fact that no young staff are coming to take their place. Nothing in the world would get them to come and work here."

Who is going to take over?

Indeed, young doctors "are free to go where they want", confirmed Petro Kondratenko, rector of Donetsk university medical faculty and working in exile at Kramatorsk on Ukrainian territory. According to him, it is up to local authorities to attract young people through offering them good accommodation
and working conditions, and sometimes even wage supplements – a luxury out of reach of the Stanitsa Louhanska hospital. "I well understand the difficulties they are having down there. But you can’t ask our young doctors to give up everything at the start of their careers", said Petro Kondratenko.

In his office in the former technical faculty of Kramatorsk, the rector has to cope with his own problems. "We used to have 6,000 students in Donetsk. Now we’re down to 3,000, and half of them come from abroad." Forced to leave Donetsk in 2014, the university also lost two-thirds of its teaching staff and all its equipment. "We’re just about managing to get things going again", he explained. The rector has no lack of projects, one of which is to develop courses in English and French. A promising initiative, but one possibly encouraging young doctors to emigrate. For students Myroslav Mikhalusov and Yevhen Lysenko, whose choice seems clear. "Canada or Germany", they sing in chorus at the university entrance. Even if, added Myroslav cautiously, "leaving is a difficult decision. Everything depends on how the situation here develops, and what impact the reform has".

"The goal of the State’s policy has got to be to keep young doctors here, stopping them from emigrating”, said Serhiy Neschyotny, head doctor at the children’s and psychological ward of the Droujkivka hospital. "I know of a young doctor from here who went off to do an internship in Slovakia. He never came back. After just two years, he was able to buy an apartment! It’s obvious why they’re leaving ...."

At the hospital in Droujkivka since 1986 and its head doctor since 1999, Serhiy Neschyotny was nearing the end of his career and had no intention of going anywhere. He was staying put, managing a team of 25 doctors and 75 nurses and care staff. The team serves a population of more than 100,000, as well as a further 11,000 displaced by the war. As in the other hospitals in the region, he complained of infrastructures creaking with age, of shortages of staff, medical supplies and drugs, and of the general decline in the level of public health. He as well found hope in humanitarian donations and irregular modernisation measures, such as the modernisation of the children’s and psychological wards, finished in January 2018.

But what concerned him was the uncertainty attached to the health reform. A budget of 8 billion hryvnias (€261 million) has been earmarked for developing a new National Health Service (NHS). How much of this budget could his hospital hope for? Would departments be merged or transferred elsewhere? How would medical tests be booked? What would be the role of his care staff vis-à-vis a GP? In Kiev, deputy health minister Pavlo Kovtoniuk promised that the situation would improve "once the reform is on track". But at Droujkivka, Serhiy Neschyotny had no idea how to declare his hospital under the new NHS. In July 2018, 149 health institutions in Ukraine had signed agreements with the NHS. These included just 9 in the part of the Donetsk region under government control and none in the Luhansk region.

In the sober office of "his" building at the hospital entrance, family doctor Vadim Dotenko echoed these uncertainties. A hospital doctor for 20 years, he had switched to being a family doctor in 2013, "by learning on the job how to deal with ailments ranging from chirodopa to infectious diseases". He deplored the lack of the equipment needed to come up with a correct diagnosis and then send a patient to the appropriate specialist. Vadim Dotenko was also worried about the numbers of new patients coming from the surrounding countryside. "As few family doctors are setting up shop in the villages, patients are having to come here. But given the state of the roads and the cost of transport, 20-30 kms is quite a long way." His fear of seeing rural areas deprived of all health services is one of his main criticisms of the reform.

"We’re already finding it difficult to attract young specialists here to a big town like Droujkivka, so just imagine what it’s like in isolated parts of the country", criticised deputy head doctor Hennadiy Iefremov. He saw the reform as being symptomatic of a reform in a rich country, little reflecting Ukrainian reality. "Our situation is already difficult. I’m afraid that it’s going to get a lot, lot worse.” Hennadiy Iefremov similarly felt in his flesh the decline of the health system, conjuring up memories of his three years spent in Cuba, as a specialist posted to a Soviet contingent. "In those days, we went out to teach other countries ..."

“Yes, our situation is difficult. Yes, the reforms raise many questions. But we need to battle on”, said Serhiy Neschyotny. "To carry on applying for international scholarships, soliciting humanitarian organisations, calling for young specialists. Working for the good of our patients. You know what they say here: hope dies last.”
"We used to have 6,000 students in Donetsk. Now we’re down to 3,000, and half of them come from abroad." Forced to leave Donetsk in 2014, the university also lost two-thirds of its teaching staff and all its equipment.
"It’s a disaster. Nobody wants to come here to take the place of the missing professionals. And I can understand why ..."
The bitter taste of clementines

If you go onto the Corsican Chamber of Commerce website, you’ll learn that “the clementines produced on the island have gained the red label, attesting superior quality differentiating them from similar products and validated by sensory analyses and tastings entrusted to a panel of consumers but also to a group of specialists”.

While the book written by Antoine Albertini does not question these tastings, it does look at the bitter social and human after-taste which such labels prefer to ignore. He raises the question of the conditions under which the fruit is produced in the plain of Eastern Corsica, the 12 km-wide and 100 km-long strip of land hosting large agricultural companies specialised in growing wine and fruit. The bulk of Corsica’s production of grapes, citrus fruits and kiwis comes from here, and production is equivalent to about half of the income the island gains from tourism.

The book in question – Les invisibles – is part of the recent revival of the tradition of literary reporting concerning labour issues centred around such (French speaking) writers as Ivan Jablonka, Florence Aubenas, Nicole Malinconi and others. It could also have claimed to be a detective novel except that the plot did not stem from the author’s imagination and that any reader wanting to know the name of the killer will remain in the imagination and that any reader wanting to

The investigators were quick to establish the victim's identity. Born in Morocco, his name was El Hassan Msarhati and he was forty years’ old. And he was basically just as invisible as any of the thousands of seasonal fruit-pickers working on the plain. But not completely invisible. A fortnight before the murder, he had worked as an interpreter for a documentary on illegal immigration. Translating the testimonial of half a dozen seasonal workers, he had suddenly stopped in order to speak about his own experience. The clip lasted just twenty-eight seconds. “I broke my hands carrying a crate of fruit and the boss sent me away because I was no longer of use. Since then, I haven’t been able to work and I can’t get back to Morocco because I’ve got no money.” He agreed to give testimony, but requested that his face be kept concealed: “Because if I speak out, they’ll put a bullet through my head.”

The book has two stories to it. The first involves the investigation which drew a blank. Despite following up a number of possible clues, the police were unable to put a name on the murderer. The exact motives of this crime will remain unknown to us. The other involves the human and social context of the work done by the seasonal immigrants. Nearly everywhere in Europe, the hardest and worst-paid part of agricultural work is done by squads of workers who compound the very precarious but legal status of seasonal workers with the even more vulnerable situation of “undeclared” workers. Albertini’s book is an irrevocable testimony against what is modestly called “immigration by choice”.

It combines precise and demanding journalistic thoroughness with a flexible, jerky style adapted perfectly to the different registers structuring the story: the police investigation, the living and working conditions of these seasonal workers, the administrative circulars of the border police. The Eastern plain of Corsica itself becomes one of the book’s characters. This former marshland was converted into a prosperous agricultural zone under circumstances linked to the history of the world. With a view to establishing a US Air Force airbase, insecticides were sprayed intensively from 1943 onwards to get rid of the mosquitoes. This led to a turning point in the mid-1950s, with the region becoming host to capitalist agriculture. This transformation of the Corsican agricultural went hand in hand with the arrival of ex-colonists from Morocco, followed on a more massive scale by an influx of Europeans repatriated from Algeria.

Describing a morning like any other one in the port of Bastia, the epilogue is a cry against our tendency to look the other way: “Nobody takes the slightest notice of the sad and tired group of men filing down the ferry gangways. With their multicoloured bags, their threadbare coats and worn-out shoes, these men to whom no one pays attention quickly merge into the background, their clothes mixing with the grey stones of the pier, the grey of the quay and the grey of the autumn sky – all the shades of their coming renunciation. They shuffle past the customs officers leaning on their cars, along the pier where HGV drivers park their trucks before embarking for Livorno or Marseille, then vanish behind the gates of the port. Several hours later, they are dropped off close to a vineyard or a clementine orchard, or perhaps a kiwifruit plantation.”

— Laurent Vogel

Les Invisibles.
Une enquête en Corse
Antoine Albertini, éditions JC Lattès, 2018

On the same subject, we would like to point out the thesis of sociologist Frédéric Décosse: Migrations sous contrôle. Agriculture intensive et saisonniers marocains sous contrat “OMI”. Available at https://hal.archives-ouvertes.fr/tel-01092682
A plea for sustainable and desirable work

In May 2017, Emmanuel Macron was elected as the 25th President of the French Republic. As soon as he took office, he began to actively promote the idea of the “liberation of labour”, a somewhat vague concept that had figured in his election campaign, and caused some controversy and concern. In his latest book, Thomas Coutrot admits from the outset, somewhat sardonically, that the expression “freedom of labour” has been bandied about in recent years to embellish certain neoliberal reforms aimed solely at future deregulation of the labour market.

The title of Coutrot’s book, “Freedom of Labour” (“Libérer le travail”), plainly attributes a more emancipatory – and anti-capitalist – meaning to the expression, as if to clarify and settle its definition once and for all. In the first of the book’s four sections, he provides an overview of the current state of the labour market based on statistical surveys of working conditions. These show that work represents a source of anxiety for more than half of those surveyed. The neoliberal organisation of the labour market, its digitisation, the standardisation of tasks, job insecurity, intensification, etc. lead to a climate of unsustainable problems that can cause significant problems for those affected by it; problems that are increasing at an alarming and distressing rate.

The second section echoes the book’s subtitle, which rings out like a challenge to the country’s leftist parties and the trade unions: “(Freedom of Labour:) Why the Left does not care and why this must change”. On this point, Coutrot identifies two currents of thought: the productivist and statist approach favoured by the proponents of Taylorism (described as “the anti-labour left”) and the concept of cooperative self-management (described as “the left without labour”). He sets out the reasons why each of these approaches has failed to achieve a democratic organisation of the labour market, an alternative system leading to autonomy, creativity and emancipation; in other words, genuine freedom of labour. Coutrot maintains that, while this disregard for a restructuring of employment was tolerable “as long as capitalism offered adequate trade-offs for subordination, [...] the damage currently being caused by the neoliberal organisation of the labour market makes it untenable”.

In the third part of the book, the author discusses managerial initiatives, suggesting that the majority of proposals to liberalise the labour market have emerged from business owners and managers. He sets out ideas put forward by “humanist” managers to challenge the concepts of Taylorism and unbridled rationalisation or to consider the potential productive benefits of employee autonomy and stakeholding. These include participative management, autonomous teamwork and the adoption of a sociotechnical approach leading to a “liberalised enterprise” culture, sociocracy, holacracy, self-governing companies, etc. In some cases such approaches have failed, while others prove that greater autonomy can go hand-in-hand with improved productivity. Nevertheless, they all constitute a positive breeding ground for the idea that non-hierarchical organisational models can bring genuine freedom to the working environment.

The fourth and final part of the book addresses the link between work and democracy. Coutrot effectively highlights the reasons why freedom at work is an issue that goes beyond the sphere of employment and why it is vital that the organisation of the labour market be seen as a political issue. He cites a number of studies that show that when autonomy in the workplace is lessened, political participation decreases. In France, a commune-by-commune cross-comparison of data on working conditions and voting outcomes in the 2017 presidential election shows a strong statistical link between a lack of autonomy at work and abstentions or votes for the far right. At a time when Europe is grappling with the rise of populism, such findings must prompt us to look for ways to increase democracy in the workplace in order to make work a tool of democracy. To this end, Thomas Coutrot recommends focusing on two promising routes: collaborative work and the ethics of care, both anti-capitalist alternatives that are outlined with reference to existing practical initiatives (the “flipped classroom” teaching method used by some teachers in France and the Buurtzorg autonomous home care teams in the Netherlands).

This thought-provoking book is a must-read for anyone questioning the sustainability of the contemporary labour environment.

— Fabienne Scandella