Conclusions
Return to work after chronic illness and the way ahead

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1. Why does the return to work following chronic illness matter?

Demographic developments including ageing and, simultaneously, declining birth rates, resulting in a shrinking workforce, coupled with an increasing prevalence of chronic illness among all age groups – but particularly for older workers – imply that more people of working age are expected to face health problems at some point during their career. Meanwhile, chronic illnesses, usually characterised by a long-term nature and slow progression regardless of whether or not there is a cure, constitute the main reasons for absence from work, as well as presenteeism at work, and could be a precursor for early exit from the labour market. In addition to the effects on health and the personal and professional setbacks to the person at the centre (as well as the indirect costs for caregivers), chronic illness and the related issue of long-term absence from work also pose challenges to employers regarding the continuity of work due to missed workdays or productivity losses. Costs can reach significant amounts when aggregated; for example, while the direct costs of work-related cancer in terms of healthcare and productivity losses can vary between €4-7 billion, the indirect costs can reach nearly €334 billion annually.[1] Furthermore, soaring sickness and disability benefits in many countries, in the face of a declining workforce, is putting further strain on the sustainability of social protection systems in Europe.

For all these reasons and more, the return to work and the occupational reintegration of individuals with chronic illness has become an important element of various policy areas ranging from employment to health and safety policies and to ones focused on social inclusion. Moreover, in addition to addressing the specific challenges faced by individuals with limiting health conditions, their reintegration into work is part of a wider European policy agenda promoting not only a healthier Europe, with active and healthy ageing involving longer working lives, but also establishing inclusive European societies in which various strategies aim at reducing the risk of the marginalisation and poverty of vulnerable individuals, as well as discrimination against them.

In this context, given the importance of the social partners in representing the interests of workers and employers and striking a balance between the two sides in the workplace, the role of industrial relations structures and actors comes to the fore in terms of how far they remain relevant in addressing and facilitating the return to work of individuals following chronic illness. This has been the core task of the book which looks at this issue from several distinct angles.

1. https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52017DC0012&from=EN (page 4).

In particular, various chapters provide a detailed picture of return to work policies and experiences from multiple governance stages, including EU, national and company levels and with a particular focus on the industrial relations actors, and zoom into the perspectives of workers going through return to work or reintegration processes following chronic illness. Six countries – Belgium, Estonia, Ireland, Italy, Romania and Slovakia – are analysed in depth to understand how the return to work is implemented and perceived by national stakeholders, social partners, managers and workers. The evidence base used for the analyses relies on mixed methodologies combining both qualitative approaches, drawing on an overview of the existing academic and policy literature, and quantitative ones exploring primary data collected in a number of online surveys and interviews and at various stakeholder events.

2. EU-level approach to the return to work

The overall analysis suggests that EU-level initiatives and industrial relations actions have, so far, been limited in the specific context of the return to work following chronic illness. This is partly due to the subsidiarity principle as employment and social policies remain a national competence. Nevertheless, a number of actions and strategies from a range of policy fields have been put forward and these have some relevance for the return to work and reintegration of individuals experiencing chronic illness. From a health and safety perspective, while EU policies have mainly focused on the prevention of occupational accidents and work-related diseases, the importance of chronic illness is increasingly acknowledged in the face of its rising prevalence in Europe. However, chronic illness is still frequently subsumed within the disability framework.

At least three recent EU initiatives are worth mentioning with a clear relevance for the return to work. The first is the recently-released Strategy for the Rights of Persons with Disabilities, which specifically refers to the workplace rehabilitation of workers with chronic illness. The second is the EU 'Beating Cancer' Plan that also addresses the return to work of individuals experiencing cancer. Last but not least, the new Strategic Framework on Health and Safety at Work for 2021-2027 has also a role to play in the return to work context.

As regards the involvement of the EU-level social partners in the return to work, the analysis points to limited action at this point. However, the social partners here consider the issue to be highly relevant, even if it is not as yet much on their agenda. It was also largely acknowledged that, in this context, EU-level action could be more appropriate for raising awareness and organising information campaigns as well as supporting national members with more practical guidance on facilitating the return to work at national, sectoral or company levels where more specific actions can be taken.

3. Approaches to and experiences with the return to work in six member states

In most of the countries studied, the existing national policies and legislative framework do not specifically or sufficiently address the return to work and reintegration of individuals with chronic illness; the target is rather those individuals who have disability status, the extent of which is assessed and certified by medical authorities. Individuals with chronic illness usually fall under a certain category of disability status when it is established that their illness has caused a partial or complete loss of work capacity.

Considering the overall policies and approaches to the return to work based on the national analyses, some commonalities may be observed. It emerges that, in most of the countries, other than Belgium which has an elaborate framework for the reintegration to work of people with non-occupational illnesses, there is no specific national policy framework addressing reintegration. Most of the time national polices consist of general sickness leave or disability provisions and quite often constitute a rather fragmented approach to the return to work in which the state usually takes the leading role in policy creation. Consultation and collaboration – let alone co-design – with the social partners or other stakeholders on the return to work or related policies remains limited and the scope for interactions between various actors depends on national legislative structures and industrial relations traditions. At the same time, the return to work lies at the intersection of several policy domains – employment, occupational health and safety, social inclusion and disability – and, as such, policy design and then implementation involve different stakeholders whose priorities might diverge. This might also complicate the coordination of policy-making on the return to work.

In some cases, the existing law accords specific roles to the social partners or other relevant stakeholders to take part in policy-making (e.g. Belgium) while in others consultations are organised in an ad hoc or voluntary manner (e.g. Ireland), if at all (e.g. Estonia or Romania). In Italy, the legal framework on the return to work is somewhat disconnected and often the social partners lack the legal expertise properly to implement the legislation at local levels. A similar situation arises in Ireland, which has a disjointed and complex benefit-setting system that is hard to navigate for workers, especially when dealing with chronic illness.

It also emerges that 'one size fits all' kinds of solutions do not work well in the context of returning to work after or with chronic illness because of sectoral, company and individual specificities that necessitate a more tailored approach on a case-by-case basis. For example, in Slovakia individual assistance to workers at company level is provided by trade unions to facilitate the return to work in the absence of focused and targeted policies. The presence of decentralised and informal channels for dealing with the issue is also common in some countries (e.g. Ireland and Italy). In Romania, the existing law only provides general stipulations as regards work reintegration and no specific measures or interventions exist for easing the return to work, despite a generous duration of fully-paid sickness leave.

The type of disease also matters as workplace or workload adjustments and the needs of individuals with musculoskeletal disorders may well differ from those of individuals with mental health conditions or cancer. In this respect, campaigning and patient support organisations or other relevant NGOs are also considered key actors as they have deeper knowledge on the specificities of particular illnesses and patient experiences and can inform policy-makers and the social partners on the precise needs and priorities of individual workers.

All in all, it is acknowledged that the return to work with chronic illness is a complex subject involving a multitude of actors and stakeholders each of whom might have a specific role to contribute in the facilitation of the overall process.

4. The role of the social partners in the return to work

The overall findings reveal mixed results as regards the role and involvement of the social partners in return to work policies and processes. On the one hand, while they find it relevant, the return to work is not yet a pressing issue for them and hence it is not surprising that their involvement in such issues is limited.

In Estonia, given low union density coupled with weak sectoral social dialogue, neither trade unions nor employer organisations have taken much initiative in return to work matters. In Romania, there is reduced involvement and collaboration, focusing mainly on financial benefits for workers, among the industrial relations actors but their role in raising awareness is also acknowledged. In Italy, regional and company-level collective bargaining on this issue is largely underdeveloped, relying mainly on the mutual willingness of trade unions, employer representatives and managers; when it happens, it is limited to large companies in specific sectors. Ireland's new-traditional social partnership ended following the recent financial crisis in 2009 and, since then, social dialogue has been weakened generally; nevertheless, the high-level social partners were able to make their input into policy development at national level regarding the employment strategy for people with disabilities. In Slovakia, the return to work is not a key topic on the trade union agenda but this is due to low capacity and a shortage of expertise rather than any lack of willingness to be more active in the field.

In contrast to the other countries, the social partners in Belgium have played a key and multifaceted role in the development of a recent dedicated return to work policy framework via the social dialogue. This is in the context of a deeply-established industrial relations setting with high rates of unionisation and collective bargaining coverage. Despite the unforeseen contract termination outcomes (so-called medical *force majeure*) implicit in the framework, the intensive and high level of interaction between government and social partners during the policy design process has put Belgium at the top of the list of the countries studied in this book where the social partners have made an important difference in the return to work.

5. Workers' perspectives and experiences during the return to work

It appears that one of the main challenges for workers in the return to work is a fear of returning without having the right support during the process. Partly this is due to the lack of necessary adaptations in the workplace or other types of (e.g. psychological) support following return. Here, a big part of the responsibility falls on employers who are either too concerned about the costs of adjustments or truly lack the capacity or knowledge to implement existing laws giving certain rights to workers. In either case, it emerges that more education and better informed employers would be more able to understand what their role is in this process and what reasonable accommodations can be made to assist workers.

As regards perspectives on trade unions, workers' rather underwhelming actual experiences during their return to work could possibly be due to workers having very high expectations of what trade unions are able to do for them in this scenario and, perhaps, because workers might consider their trade union representative simply as a means to realise gains on their behalf behind the scenes. A shift in mindsets might be necessary here as more could be achieved. At the same time, trade unions seem to struggle to reach such workers because of the individualised nature of the context of illness and because of privacy concerns, making situations harder to collectivise. Nevertheless trade unions should continue to be proactive by informing workers about their rights and raise awareness about the issues, possibly also by joining forces with other campaigning and patient support organisations.

The other major issue is what the experience of chronic illness makes workers think about going back to work. It is possible that dealing with a chronic illness makes workers realise their vulnerabilities and rethink the importance of time (and life) and thus it can lead to a desire to 'slow down'. This is where policy campaigns to make working lives longer give an uncomfortable message by incentivising workers back to work in the context of the requirement for labour to sustain social security systems. At the same time, working after chronic illness can also be part of the rehabilitation process as it can make workers feel valued despite their vulnerabilities or reduced capacity.

6. Return to work in the Covid-19 context

Here, there are several countervailing effects in play. While the pandemic has added further complications to the return to work process, it might also offer ample opportunities with which to facilitate it.

On the one hand, because of overwhelmed and reduced healthcare services in hospitals during lockdowns, as well as the likely avoidance of medical centres by individuals due to a fear of virus propagation, the pandemic may have delayed the early detection as well as treatment of chronic diseases such as cancer that would otherwise have been monitored and caught. Moreover, recent studies hint at the long-term impacts of Covid-19 on individuals already experiencing chronic conditions and who are at mild to

high risk should they catch Covid-19 (we refer here to Long Covid; for more on this, see the Introduction). Limited social (and professional) contact due to lockdown measures can also extend the recovery process and the reintegration to work of individuals with chronic illness. The pandemic, therefore, might have further compromised the return to work process of individuals with chronic conditions.

On the other hand, mandatory teleworking in certain jobs, where this is possible, and the flexibility that this entails might well offer new possibilities to individuals with chronic conditions in the sense of being able to perform their work from home. Prior to the pandemic, it might have been harder to negotiate this with employers.

In some cases, the pandemic context can also offer the opportunity to rethink existing social security and social protection systems and to consider adapting them to the new context generated by Covid-19. Ireland is a case in point: up to now, there has not been a statutory sickness pay scheme in place in the country but the government has been considering introducing related reforms in a reflection of the devastating health, social and economic circumstances created by the pandemic.

7. Policy considerations and the way forward

Considering the overall involvement and perspectives of the various stakeholders across the different countries analysed, a number of policy considerations come forward.

First and foremost, there is a need to promote a proactive approach to the return to work in which workers are accompanied through effective and transparent communication of policies and procedures which, in turn, help them better navigate what appears to be an already complex process. The overall approach should also take into account the specific needs and priorities of workers, depending on the illness, while accordingly thorough discussions on workload and workplace adjustment, matching the requirements of the reasonable accommodation regulations, would be highly beneficial in facilitating a successful return to work. It would also be helpful if the EU's reasonable accommodation legislation, which currently addresses the needs of disabled workers, could be formally extended to cover workers who are chronically ill. Employers, particularly managers in small and medium enterprises, should also be guided and informed along the way.

Despite the currently limited involvement of the social partners in return to work issues, it is largely believed and expected that effective social dialogue can help to design and facilitate return to work and reintegration policies. As the voice of workers, there is also the important role and responsibility of trade unions to raise awareness on the issues and accompany workers at all levels. However, this requires a deepening of the knowledge of the social partners on the existing legal framework, a strengthening of multi-stakeholder cooperation and coordination across different layers of policy-making and implementation, and an intensification of interactions between the social partners as a means of discussion and exchange on particular aspects of the return to work.

There are also challenges in tackling the return to work through social dialogue because of the private and sensitive nature of the context of illness and since workers away from the workplace as a result of sickness leave are actually on the margins of social dialogue procedures. This is where trade union representatives could play a more proactive role in accompanying and engaging with workers while respecting sickness and recovery periods. Overall, however, experience from the countries studied suggests that having a broad national framework enforcing basic rights and requirements, complemented by a tailored company-level approach, could actually work rather well. In particular, sectoral specificities and company-level characteristics are likely to play an important role in a better targeting of the return to work process. A further possibility could be to push for collective agreements at company level.

It also appears that, once the recovery or recuperation period is over and workers are ready to think about going back to work, the process of return needs to be handled quite 'gently' in a way that allows workers to come back in a gradual and progressive manner – be it in terms of work time and tasks or level of responsibility. Flexibility is also important in cases where individualised accommodations might be necessary, as long as the flexible approach follows from agreed principles (or ones accorded by law) around job security, income security and so on. It is well worth giving these sorts of issues formal consideration either in existing dialogue processes and/or in terms of how legislation responds to the concerns of both workers and employers in this area.

At EU level, the key role continues to lie in awareness-raising on return to work issues as well as providing information and practical guidelines to be transmitted to national, sectoral and company levels. The potential development of a European charter on the return to work, where all relevant information could be gathered, is an option. Another avenue is to incorporate the issue into the European Semester process in which member states would closely monitor the employment and social inclusion of individuals with chronic illness. The social partners could also more proactively participate in this process.

Finally, further multidisciplinary collaborations will be of help in increasing knowledge and expertise on the return to work after or with chronic illness. Such collaborations would allow the exchange of best practice and inform policy-making. Deeper cooperation between the social partners and campaigning and patient support organisations could be especially enriching for both sides. Furthermore increased efforts to collect harmonised data on the return to work and chronic illness will also be needed to allow a proper measurement of the scale of the issues so that informed decisions may be made about them in the future.