

Employment practices and data protection – information about workers’ health

Response to ICO Consultation

Introduction

The Trades Union Congress (TUC) exists to make the working world a better place for everyone. We bring together the 5.5 million working people who make up our 48 member unions. We support unions to grow and thrive, and we stand up for everyone who works for a living.

We welcome the opportunity to respond to the Information Commissioner's Office (ICO) consultation on employment practices and data protection regarding information about workers' health.

We agree with the ICO that health information is some of the most sensitive personal information that might be processed about workers. An online resource with topic-specific guidance on employment practices and data protection could be vital to workers, employers, trade unions and trade union representatives.

But the draft guidance in its current form would not adequately support all the groups who might seek to use it. Despite the ICO's role 'to uphold information rights in the public interest'¹ the employer-focused framing and language; the lack of detail on the ethical principles involved when making complex decisions about workers' health data, and the omission of information about the benefits of involving trade union representatives and activities, such as meaningful dialogue, consultation and collective bargaining and just some of the problems outlined in our consultation response below.

To ensure the final guidance on employment practices and data protection regarding information about workers' health is a document that helps the ICO to uphold information rights in the public interest, the TUC calls for the ICO to:

- i) Change the framing and language to make it just as applicable to workers as it is to employers. The guidance does well to talk about the power dynamics inherent in any employer relationship. This needs to go further. Change the framing so that it is more in line with employers upholding their duty of care to employees and treating their health data according to this duty of care.
- ii) Talk about unions. Collective bargaining provides an excellent framework for involving workers in meaningful consultation about how their data is used.² Of those not covered by an agreement, there may still be an active branch in the

¹ ICC (2023) *What we do* [online] Accessed 31st January 2023 Available at: <https://ico.org.uk/about-the-ico/what-we-do/>

² TUC (2019) *A stronger voice for workers: How collective bargaining can deliver a better deal at work* [online] Accessed 31st January 2023 Available at: <https://www.tuc.org.uk/research-analysis/reports/stronger-voice-workers>

workplace, including a health and safety rep that can facilitate negotiation and help workers make empowered decisions.

- iii) Consider that readers will be engaging with the guidance with limited time. Allow for better navigation through the document. Consider repeating items for reiteration and to avoid readers missing key points. Cite all relevant legislation you mention. Provide links to this.
- iv) Make more specific reference to equalities groups, who already experience barriers in when accessing their rights, including in the workplace like employment, human and data-related rights. One example of an employer using data and employment practices positively would be the inclusion of ethnic data monitoring in accident records, to allow sickness and accident reporting to show any patterns of discrimination in the workplace which could then be addressed by the employer.
- v) Explain the legislative landscape more fully. There does not appear to be full and complete guidance on how common law currently affects the sharing and processing of workers' health data. Nor does the guidance mention relevant health and safety legislation. The key point to note is employers have a legal duty to consult with staff on issues affecting their health and safety and this will play in to actions affecting their health data. The guidance must explain this.

Clarity and readability

This guidance is not easy to understand. The framing, language, and examples would benefit from revision to make this guidance more effective for readers who are not employers, such as workers and those in worker support roles like occupational health practitioners.

1.1. While the title suggests the guidance will be a broad guide on employment practices and data protection regarding information about workers' health that could be used by employers, employees, unions or union representatives, the text is clearly targeted towards employers. A deeper consideration of who this text is for in the context of the ICO's role 'to uphold information rights in the public interest' will show that the current framing and language, including using the second person 'you' and plural pronoun 'we' - to mean employers, are not appropriate for this text unless the ICO plans a further guidance document for workers and worker support roles. Currently, the overall framing of the guidance as employer-focussed makes it hard to navigate for workers and union representatives.

1.2. The language the used often stops short of describing the ethical principles involved in complex decisions by employers about how workers' health data may be used. The mention of the inherent power imbalance between workers and employers on p.9 is welcome, though not sufficient. Hypothetical situations and example boxes are presented without the vital stages of worker consultation and consideration to which employers are morally, if not legally bound. For example, the concept of consent is presented only as a tool that constitutes a legal basis for collecting and using workers' private data: 'If you think it will be difficult for you to show that consent has been freely given, you should consider relying on another lawful basis, such as legitimate interest'. This lacks information on the impact on workers and their rights when consent is perceived to be expected. Language that reflects both the legal and the moral or ethical principles involved in such decisions would better prepare readers for real-life decisions of this type, for example: 'If workers do not or cannot consent to giving their data freely, due to the power imbalance between workers and employers, access issues, personal choice or any other reason, then without another legal basis, you may not use their data'. This problem of language that does not consider workers' rights and employers' obligations for best practice is consistent though the text.

1.3 The example boxes in yellow often do not show the complete range of issues an employer would need to consider in a real-life case of the example given, nor do they reiterate the points made in the preceding section of guidance. On p.10, in the example of the medical firm offering health screening for its staff, the example suggests that consent would be a lawful basis if the firm makes clear that the data will not be used for any 'performative evaluation purpose'. However, under the principle of purpose

limitation, the firm would also need to make clear that the data collected for this optional personal health screening would not be used for any other purpose at all. By only giving readers part of the facts relevant to an example, this guidance fails to inform them of the constellation of issues they would have to consider in a real-life case of the example. Also, some of the concepts in the example boxes (and wider text), like explicit consent, would benefit from being emboldened as they are important ideas that need differentiating. This would focus the minds of readers who are employers and only look to general consent.

1.4 This draft guidance and the detail contained within is appreciated, but there is a concern that at 47 pages long, readers may not be able to take in the entire document.

Relevance

There is much missing from this guidance including the role of trade unions, health and safety (H&S) representatives, or relevant health and safety legislation.

2.1. The guidance does not currently describe the benefits to both workers and employers of engaging with staff in meaningful dialogue, consultation and collective bargaining via trade unions. One example of this would be the need for trade unions to have access to collective reporting of data on injury and sickness to check for patterns and concerns. In the past, this has been useful for unions to identify sick building syndrome, for example, where a range of symptoms thought to be linked to spending time in a certain building, most often a workplace, is present among the workforce, but no specific cause can be found.

2.2. Of particular concern, is the further lack of any mention of an employer's duty of care to their workers or a worker's right to be consulted on the introduction of new systems and proceeds that might affect their rights. One example of this is the section on health monitoring technologies. Despite this type of monitoring being highly intrusive and the data concerned being of a special category, the section begins: 'As an employer, you may decide to use health tracking technologies to help monitor the health of your workers.' Decisions of this type taken without worker consideration or consultation are unfair and, without an impact assessment or in cases where the employee has a reasonable expectation of privacy, they could be unlawful. There is no guidance in relation to the need for collective and individual consent regarding the introduction of such technologies. There is a wide potential for discrimination in this area as trade unions have found that Black workers, women and disabled workers are often more likely to be monitored in a way that affects them negatively.

2.3 The guidance would benefit from discussing how far and to what extent employers, especially when they are data controllers, need to inform and consult with workers and health and safety (H&S) representatives. A full description of the role of H&S representatives and their relevance in so far as they sit at the intersection of employment law, health and safety law and data protection law would be a necessary improvement to this guidance. Where artificial intelligence, workers' health, and the employment relationship are involved, trade unions, and their representatives can be a useful third party for supporting workers to protect their rights and ensuring the employment relationship is a positive one through consultation and collective bargaining. The role of a H&S representative is to negotiate on the appropriate H&S processes a workplace needs to have in place. Consulting on, for example, how an employer seeks to obtain, manage and use health records for workers would be something these representatives would be well-versed in. There is repeated mention of human resources (HR) teams in the guidance, but HR teams do not have to facilitate everything – trade unions can help employers navigate employment and data protection law. Also, there should be more reference to agency workers in order to capture all forms of employment relationships.

2.4 Of particular concern, is the guidance's failure to mention relevant health and safety legislation. There is legislation on employers' obligations to share some data with union health and safety representatives within a unionised workforce, contained in The Safety Representatives and Safety Committees Regulations 1977. There are different laws when a workforce does not have union recognition, the Health and Safety (Consultation with Employees) Regulations 1996, and different legislation where there is no union presence at all, known as the ICE regulations. The key point to note is employers have a legal duty to consult with staff on issues affecting their health and safety and this will play in to actions affecting their health data. The guidance must explain this.

Level of detail

3.1 The guidance sometimes references things it doesn't explain. There is a question about whether an employer knows whether something is a 'high risk' unless it undertakes a DPIA, which it suggests is done if you think something is a high risk - but the term 'high risk' is not explained or defined. This could cause confusion.

3.2 While the examples include a good variety of different sectors, they lack the benefit of sector specific knowledge. The section from page 22 on sickness records should acknowledge the inappropriate use of rewards and incentives for employees to maintain 100 per cent attendance. Trade unions in the education sector have recorded cases in schools and colleges where employers adopt similar attendance patterns for staff as they do for students, without understanding the difference in the relationship

as they are the employer of one group, but not the other. This approach can also damage the mental health and morale of those who have legitimate reasons for being absent.

3.3 Throughout the text and the examples there is not enough consideration given to the impact of bad practice and poor decisions by employers on workers. For example, on page 42: 'a worker is equipped with a wearable that tracks their physical activity for health and safety reasons.' This example is extremely flawed. There are very few cases where a warehouse worker would be tracked for any other reason than to measure product picking times. In the past this practice had led to unrealistic expectations around productivity, impossible targets, and discrimination³. But this example presents this decision as simple and benign, makes no mention of what an employer might also need to consider in terms of the impact on workers of such technology.

Usability

4.1 More web links to other related concepts and definitions, repetition, and examples that reflect more than one issue may help to navigate the document.

Cases, examples, and real-life scenarios

5.1 Although this does not feature in the guidance, our unions told us that working parents face particular challenges around their health data being shared. In a 2022 survey on maternity rights, an education trade union found that of the over 3500 members surveyed, many had experienced mishandling of their health data by employers. This included data being shared with a third party, in some cases several parties without a lawful reason for doing so:

"I told my line manager at 13 weeks as I had been feeling ill. They then disclosed my pregnancy to the head, deputy and HR immediately, before giving me the opportunity to do this myself, despite saying I would. I was then made to tell other senior members of staff when I wasn't comfortable doing so because I was going on a trip with them despite another staff member on the trip already being aware."

³ *The Guardian (2022) *Amazon chews through the average worker in eight months. They need a union* [online] Accessed 27th January 2023 Available at <https://www.theguardian.com/commentisfree/2022/feb/04/amazon-chews-through-the-average-worker-in-eight-months-they-need-a-union>

"I was due to change line manager and told the old one who then told the new one before I had the chance to."

"There was a bit of pressure to disclose my pregnancy to the rest of the department to advertise my role."

"She informed leadership before I was 12 weeks and they told others."

"I had to disclose my pregnancy much earlier on than I would have liked (before I told my own mum!) Because the school is insistent on providing details of any medical appointment you need to take."

5.2. There was also evidence of the confidentiality of workers' private health data not being considered when processes for recording information were being chosen:

"Our HR have a white board up on their wall where they write down all the people who are pregnant, their due dates, when they start mat leave etc. I informed my HT early that I was pregnant before I'd told other staff and even family. Some staff approached me and asked me if I was pregnant before I was ready to share with everyone. They had seen my name on this whiteboard."

"They also found that workers' rights to privacy and to have their health data kept confidential seemingly came second to things like employer policy, concerns about process, senior staff wishing to be informed, or perceived convenience for other members of staff."

5.3. In other instances, workers' health data was photocopied and kept in paper form, but workers were uncertain about the need for this and unclear on how confidentiality was prioritized as part of this process:

"I had to photocopy my medical pregnancy records to prove where I was for appointments and that I was genuinely ill. I find this a breach of confidentiality. They even photocopied scan results."

5.4 Sometimes, special category health data was disclosed to someone else, overheard by staff, and then found its way into formal human resources processes:

"There is very little offered in terms of breastfeeding in my school. It is not even considered discussing. Although once I stopped, as I was discussing my difficulties with another mum about weaning the baby off. The business manager overheard this conversation and emailed this to my male line manager that I had now stopped breastfeeding as part of my return to work form, which I thought was very inappropriate"

5.5. This survey by a TUC affiliate union in education included guidance to both employers and workers about how working parents' health data should be used. The ICO could use this guidance, its format, framing and content, in improving its own guidance on employment practices and data protection regarding information about workers' health.

Disclosing your pregnancy and protecting your rights to privacy – guidance for workers

You should be able to disclose your pregnancy and any pregnancy loss without fear of being disadvantaged or discriminated against, but it is up to you whether you wish to inform your employer of your pregnancy in the early stages. Please be aware that you're only entitled to a risk assessment or to the statutory protection from pregnancy discrimination once your employer is made aware of your pregnancy.

You are fully within your rights to ask your employer to keep the knowledge of your pregnancy - and any related information - confidential only to those who need to know for health and safety purposes. Information about your pregnancy and health is special category data, which means that in the absence of your explicit consent, your employer may share the information with a third party only if there is a fair and lawful basis for doing so. The latest time that you can tell your employer that you are pregnant is the 15th week before your due date.

Processing pregnancy and maternity information – guidance for employers

Once a woman is aware that she is pregnant, she will judge when she wishes to inform her line manager or employer and other colleagues, students and parents. She is not obliged to tell her employer of her pregnancy until the 15th week before her due date, but most women disclose their pregnancy at a much earlier stage. A key reason for informing her employer of her pregnancy is so that arrangements can be made to ensure that her workplace and working conditions are safe for her and her baby. There are many reasons that a woman might not disclose her pregnancy in the early stages.

The pregnancy might not be wanted, the woman or her foetus might be unwell, she might be afraid that she is going to be subjected to discrimination on grounds of her pregnancy, she might have previously miscarried and want to make sure that her pregnancy reaches a particular stage before she shares her news. Information about an employee's pregnancy and health is special category data, which means that in the absence of explicit consent, an employer may share the information with a 3rd party only if there is a fair and lawful basis for doing so.

Once a woman disclosed her pregnancy to you, it is important that you discuss with her whether, when and to whom she wishes her pregnancy to be disclosed. We have heard of women educators being pressured to disclose before they are ready, of having their news shared without their consent before they have informed their family. Conversely, some women have been instructed not to tell parents even though they are obviously

pregnant. An individual risk assessment will need to be undertaken and reviewed in line with regulation 16 of The Management of Health and Safety at Work Regulations 1999. The Health and Safety Executive has some very useful guidance for employers on how to go about this: <https://www.hse.gov.uk/mothers/employer/risk-assessment.htm> Do let me know the employee know you intend to undertake the initial assessment.

Disclosing your postnatal depression and protecting your rights to privacy – guidance for workers

You should be able to disclose your postnatal depression without fear of being disadvantaged or discriminated against, but it is up to you whether you wish to inform your employer of your condition. If you suffer from post-natal depression which is likely to last more than 12 months, your illness may fall within the legal definition of disability, which means you would be protected from discrimination for reasons related to the disability if your employer is aware of your condition.

You are fully within your rights to ask your employer to keep the knowledge of your condition - and any related information - confidential only to those who need to know for health and safety purposes. Information about your health is special category data. This means that in the absence of explicit consent, an employer may share the information with a 3rd party only if there is a fair and lawful basis for doing so.

Processing pregnancy related health information – guidance for employers.

Information about an employee's pregnancy, the progression of her pregnancy and any pregnancy related health conditions is special category data. This means that in the absence of explicit consent, an employer may share the information with a third party only if there is a fair and lawful basis for doing so. Once a woman disclosed a pregnancy related health condition to you, it is important that you discuss with her whether, when and to whom she consents this information to be disclosed.

Conclusion: other suggestions

6.1 Change the framing, language and make it just as applicable to workers as it is to employers. The guidance does well to talk about the power dynamics inherent in any employer relationship. This needs to go further. Change the framing so that it is more in line with employers upholding their duty of care to employees and treating their health data according to this duty of care.

6.2 Talk about unions. Some 26 per cent of UK workplaces are covered by a collective bargaining agreement. Collective bargaining provides an excellent framework for involving workers in meaningful consultation about how their data is used. Of those not covered by an agreement, there may still be an active branch in the workplace, including a health and safety rep that can facilitate negotiation and help workers make empowered decisions.

6.3 Consider that readers will be engaging with the guidance with limited time. Allow for better navigation through the document. Consider repeating items for reiteration and to avoid readers missing key points. Cite all relevant legislation you mention. Provide links to this.

6.4 Make more specific reference to equalities groups, who already experience barriers in when accessing their rights, including in the workplace like employment, human and data-related rights. One example of an employer using data and employment practices positively would be the inclusion of ethnic data monitoring in accident records, to allow sickness and accident reporting to show any patterns of discrimination in the workplace which could then be addressed by the employer.

6.5 In section 8: *what about occupational health schemes* a reminder that occupational health records are confidential and that managers (including managers who are themselves health professionals as in NHS Trusts) should not have access to them without the consent of the worker (other than in an exceptional case) even if the occupational health department is 'in-house' and directly employed. There have been cases reported to the Faculty of Occupational Medicine's ethics committee where an employer has wrongly asserted that they have the right of access to occupational health records relating to their workers without consent since they 'belong' to them because they have been made by their own employees in-house.

6.6 The legislative landscape is only partially explained: there does not appear to be full and complete guidance on how common law currently affects the sharing and processing of workers' health data. For example, on p.25 *What about occupational health schemes?* the ICO is reminded that the established common law rule is that occupational health practitioners should not disclose confidential data about a worker to an employer without the worker's consent or a court or tribunal order.