

Collecting Global Employee Disability Data

The challenges and enablers
for global disability-smart
organisations

**A research project by Business Disability Forum
sponsored by HSBC.**



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Foreword by Diane Lightfoot, CEO, Business Disability Forum

The saying goes that we manage what we measure. But how do you even begin to measure disability in your workforce on a global scale?

When it comes to gender, the case is clear: measurement drives transparency, scrutiny and ultimately, results. So, it follows that measuring disability should have a similar impact. But measuring disability is inherently much more difficult. Over 90% of disabilities are not immediately visible, and how to encourage your workforce to share is one of the most frequently asked questions of our Advice Service. Add on the complications of a global lens – cultural and language differences and navigating country legislation which means that you can, can't or must ask about disability – and you have a heady cocktail of complexity.

If it's this difficult, why bother? And why does it matter anyway? Arguably we can only drive change – and close the disability employment gap – if we can get an accurate picture of who is in our workforce already. Understanding who is in our workforce can also enable us to support everyone effectively – to understand the effectiveness (or not) of our processes and identify areas where more support is needed. And finding the right tools – and time – to measure will only be effective if it is supported by an organisational culture that normalizes the conversation around disability in the context of those wider cultural complexities and which encourages people to ask for what they need.

In our Great Big Workplace Adjustments Survey in 2019, 34 per cent of those without adjustments said they did not make requests because they were worried their employer might treat them differently.

Put another way, that's more than a third of the workforce who are not operating as effectively as they could be because they are afraid to ask for the support they need. Here, perceptions are reality – and if the perceived benefits of asking for support do not outweigh the perceived risks, employees with disabilities will continue to work around, to cover and – worse – risk falling out of the workforce.

So how and where do you start? As we set out in our 2020 report "Towards a Disability Smart world: Developing a Global Disability Inclusion Strategy", almost all organisations are at the start of their global inclusion journey – and in such a new area, to begin is to lead. The same report memorably quoted "Focus on intentions, not perfection" and that message is equally valid in the context of global disability data monitoring: do not let the fear of not being perfect prevent you from starting.

I am enormously grateful to our long-standing friend and Partner HSBC for supporting this report and the insight that informs it as the first step in identifying the issues and what we need to do to address them. My thanks too to our steering group of Partners and Global Taskforce Members for sharing their experiences and challenges to inform their report. It is the richness of this real life and practical experience that really brings the data – and the challenges! – to life.

I hope you enjoy the report and find it stimulating and thought provoking – and that, wherever you are on your data gathering journey, it encourages you to take the next step.

Diane Lightfoot, CEO, Business Disability Forum



Foreword by Ewen Stevenson, Group Chief Financial Officer, HSBC

At HSBC, our purpose is to open up a world of opportunity; for all our stakeholders - our customers, our colleagues and the communities in which we operate.

Having a more accurate view of our diversity profile, including disability, will enable HSBC to have the best possible understanding of our people. And with this, how we can better help and support each of them to thrive in their careers.

Having acquired single-sided deafness a few years' ago, championing disability in the workplace is a very personal cause for me. The Business Disability Forum has been a great support to me and to HSBC on our journey to become a better and more disability confident employer.

Having great data is a core foundation in that journey. With the right data, our progress towards disability confidence at HSBC will be much faster, more measurable and better targeted.

I would like to extend my warmest congratulations to the Business Disability Forum's Global Disability Data Working Group who have helped create this report. It is packed full of great insights from Global Diversity and Inclusion Leads on how best to capture employee disability data as well as what data is being collected in their organisations. Importantly, the report contains a summary of key challenges which will likely be encountered and how to overcome them.

This report also highlights how our progress towards Disability Inclusion can be accelerated by working together to share our progress and address challenges.

Ewen Stevenson, Group Chief Financial Officer, HSBC

Contributions and support for this research

Many organisations gave Business Disability Forum their time and support in putting this report together, via participation in the Global Disability Data Working Group – a subgroup of Business Disability Forum’s Global Taskforce - and in-depth interviews:

Accenture

Alexander Mann Solutions

Allianz

Anglo American

Baker and McKenzie

Freshfields

GSK

HSBC

Lilly

LinkedIn

Shell

Unilever

We would like to thank them, along with the anonymous participants of the online survey, for all their time and support.

We particularly thank our Partner HSBC for sponsoring this research and report and for Co-Chairing Business Disability Forum’s Global Disability Data Working Group.

Executive summary

Through this research, we aimed to understand the reasons global organisations gather employee disability data, the common challenges associated with its collection and also to highlight the things that have been helpful to any progress organisations have been able to make.

This research has been undertaken in partnership with Business Disability Forum's Global Disability Data Working Group (Working Group), a dedicated subgroup of our Global Taskforce, whose purpose is to uncover key challenges and promote best practices associated with the collection of employee disability data worldwide.

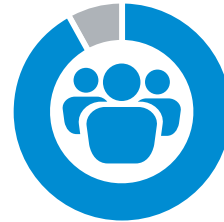
For this research, we drew on the experiences and opinions of Global Diversity and Inclusion (D&I) Leads, in a number of formats. These included Working Group discussions, depth interviews with Working Group members and an online survey, which was promoted to the BDF Global Taskforce, all BDF members and made publicly available, so that it was open to anyone who held Global D&I responsibilities to respond.

The first question the research explored was global organisations' purpose for global data collection.

The top reasons that survey respondents gave, were as follows:

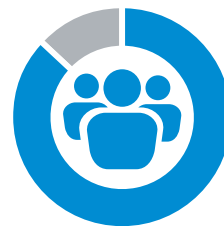
89%

"To advance the inclusive culture of our organisation".



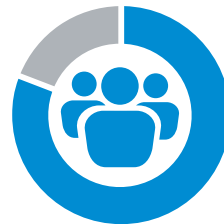
86%

"To understand how many employees have a disability".



84%

"To encourage more employees to share that they have a disability".



Organisations that had been collecting Global Employee Disability Data for some time, expressed the importance of being clear from the outset about why they were doing so. Clarity of purpose was said to save time, energy and resources. It also led to greater employee engagement when enabling employees to share their data, when the purpose and benefits of the exercise were made clear to them when they were invited to answer questions about disability.

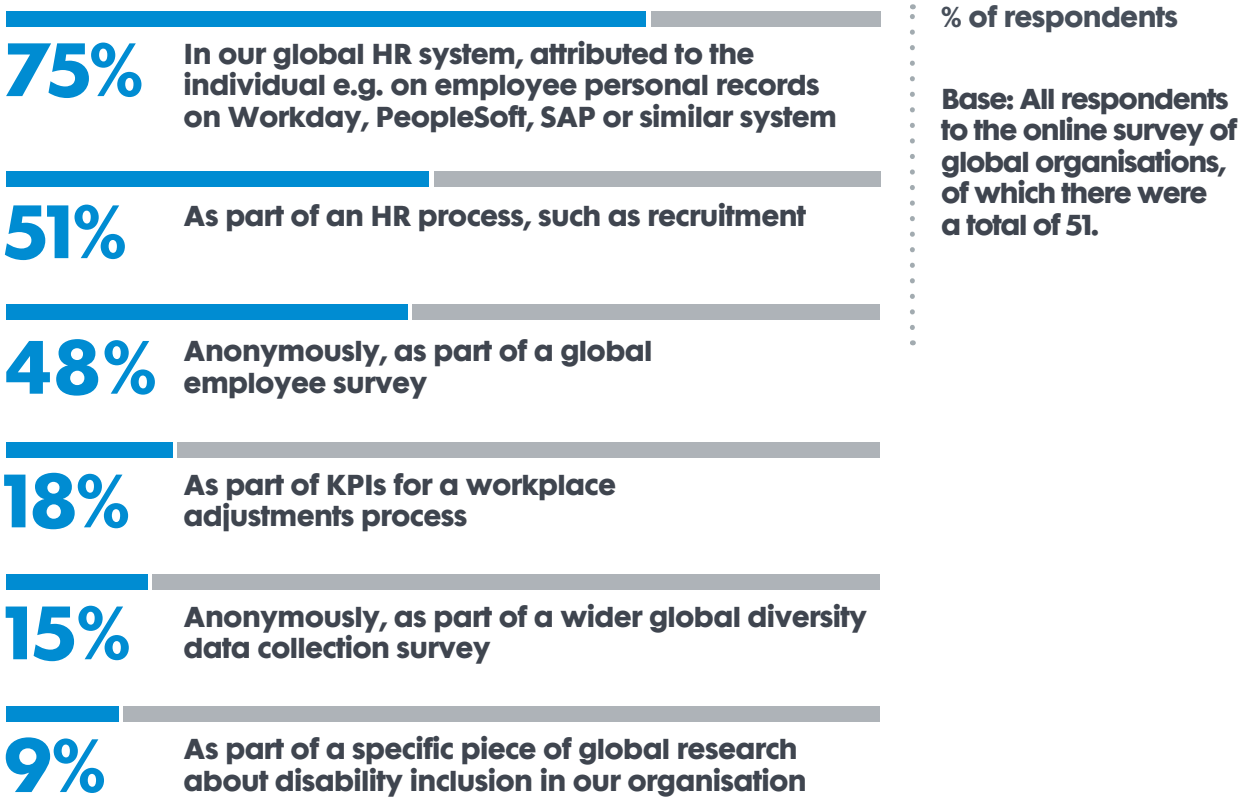
67% of survey respondents were already collecting Global Employee Disability Data in some form. Amongst those organisations that were not currently collecting data, 44% said they had the intention to do so within the next 18 months.

This demonstrates the growing importance of employee disability data to global organisations.

The second question the research explored, was what global organisations collected.

As might be expected, in-country employment law, data privacy law, regulatory frameworks, and government quotas were a strong determinant of what was collected and the language and terminology that was used. If data was being collected voluntarily e.g. because an organisation was trying to determine how many people with disabilities were employed globally, respondents typically adopted the United Nations definition of disability, the World Health Organisation definition of disability, or their own global definition/question e.g. “Do you consider yourself to have a disability or long-term condition?”. Workplace adjustment data and employee opinion data was also collected by some global organisations, which provided more insightful and actionable data, to improve the working lives of people with disabilities.

When asked how global organisations collected employee disability data, the survey respondents reported the following:



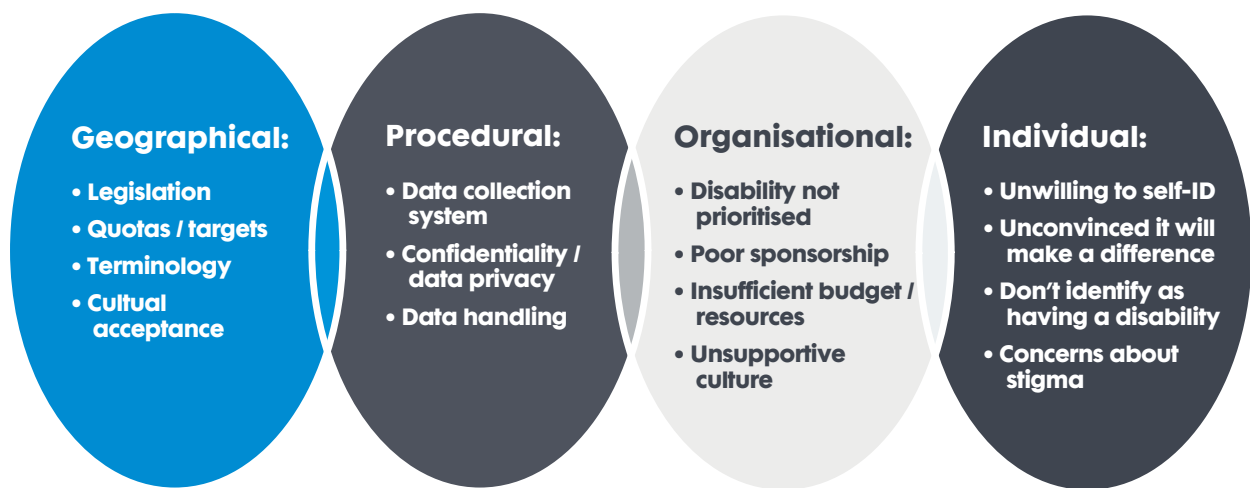
Through discussions with the Working Group and the depth interviews, it was also apparent that the data capture approaches may vary significantly across a global organisation. In the absence of a global Human Resource Information System (HRIS) that the organisation has implemented as its one 'source of truth', the reality was that various localised approaches were created, to meet the local data requirements.

All research participants were able to identify multiple challenges with collecting Global Employee Disability Data as summarised below:



It is noteworthy that the two most frequently selected responses from the survey pertained to individual employee attitudes or beliefs. This is a reminder that amongst all the organisational issues that Global D&I Leads need to navigate, and which a lot of the research discussions focused on, the final decision about whether or not to self-identify is an individual decision.

Through the Working Group discussions and the depth interviews, four clusters of challenges emerged, which are discussed in section 4 of this report:



Finally, the research asked about the key enablers to organisations getting started and building momentum with Global Employee Disability Data collection. Combining the responses from the survey, the Working Group discussions and the depth interviews, four 'building blocks' were identified.

In brief, these are:

Purpose: A clear and compelling reason, or set of reasons, why Global Employee Disability Data collection is important, and what it is intended to achieve.

Fundamentals: The globally consistent and locally resonant terminology, systems and resources, which makes Global Employee Disability Data collection work.

Leadership: Sponsorship, role modelling and accountability at the most senior level(s), which position disability inclusion as a 'call to action' that impacts everyone.

Culture: An organisational culture of psychological safety and trust, which enables employees to talk openly about disability and lived experience, without fear of detriment.

These building blocks include establishing clarity of purpose and getting in place the fundamental logistics of a global data collection exercise.

However, they also include the vital role of leadership and organisational culture. Leaders who are accountable role models and who position disability as something that impacts everyone, are able to set the organisational tone about disability inclusion. They have an important part to play in creating a psychologically safe environment that gives 'permission' to employees to talk about disability, share their lived experiences and ultimately to use their data to work towards becoming a global disability-smart organisation.

Introduction and approach

Introduction

Many global organisations seek to understand the characteristics and identities of their workforce.

There are various drivers for the interest in this information and a range of intentions in terms of how the insights will be used. In the case of employees with disabilities, this data can enable an evidence-based approach to global disability-smart actions and initiatives within organisations. Ultimately, it has the potential to improve the working lives of millions of people worldwide, who may experience barriers to their ‘full and effective participation’ in the workplace [1].

However, the collection of Global Employee Disability Data is a complex area and many organisations do not know where to start. The Global Disability Data Working Group (Working Group) was established as a task group of Business Disability Forum’s Global Taskforce. Its purpose is to uncover key challenges and promote best practices associated with the collection and reporting of employee disability data worldwide.

In this initial research we aimed to understand the reasons global organisations gather employee disability data, the common challenges associated with the collection of global disability data and also to highlight the things that have been helpful or vital to any progress organisations have been able to make.

1 UN Convention definition of disability: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

For the purpose of this research, when we refer to 'Global Employee Disability Data', we apply a broad definition. This includes information on whether employees consider themselves to have a disability, what type of disability they have, whether adjustments are required to perform their role and/or employee engagement information from disabled employees about how they feel about their workplace. Each of these data types can provide important and different insight for global organisations. We hope that this report, which shares the solutions and best practices that have been successfully deployed by global organisations, will enable positive change for disability-smart workplaces.

Research objectives and approach

The purpose of this research is to understand the following:

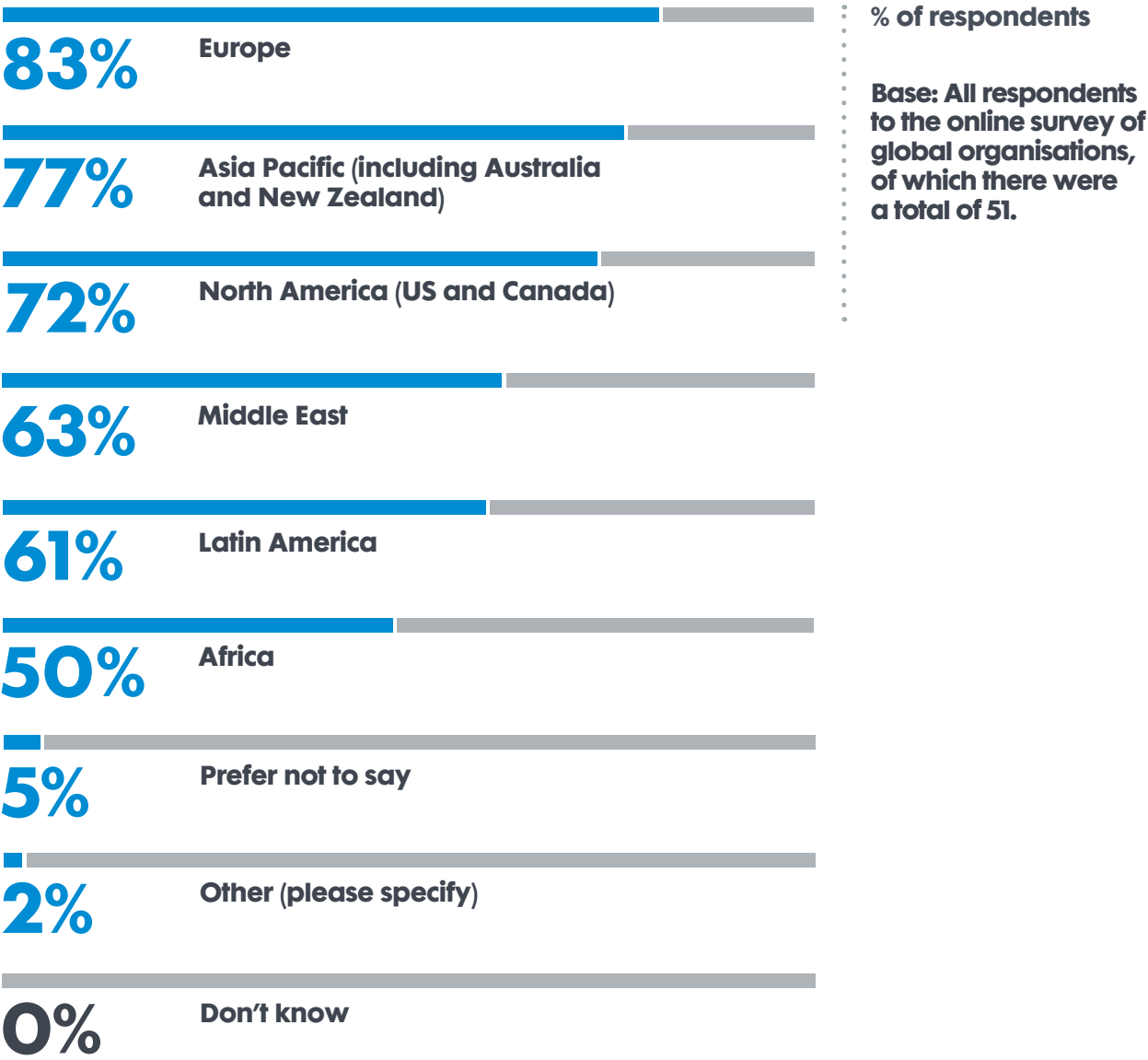
- The reasons why global organisations collect employee disability data
- What they collect
- How they collect it
- The key challenges associated with collecting Global Employee Disability Data
- The key enablers associated with collecting Global Employee Disability Data

The report is informed by three types of research, which drew on the experiences and views of D&I leads in global organisations. A combination of qualitative and quantitative methods was used, as follows:

- 2 group discussions at Working Group meetings
- 10 individual depth interviews with members of the Working Group
- An online survey distributed amongst our membership and partner organisations, and openly on social media (via LinkedIn), which received 51 responses

The contributors represent organisations that employ people in every region of the world, which reflects the global intention of the research.

In which of the following regions does your organisation employ staff?



About this report

This report highlights the opinions and experiences of global disability leads in the collection of Global Employee Disability Data.

The report is structured to align with the research objectives, which are intended to take readers on a journey from the purpose of collecting data, through the practical considerations and challenges, and ultimately to some enablers and good practice suggestions. It is structured as follows:

Section 1: Why do organisations collect Global Employee Disability Data?

Exploring the motivations and drivers for doing this.

Section 2: What Global Employee Disability Data do organisations collect?

Exploring the standardisation, type and definitions used.

Section 3: How do organisations collect Global Employee Disability Data?

Exploring the approaches and tools used to collect data.

Section 4: Key challenges to collecting Global Employee Disability Data

Exploring the main areas of challenge identified through the research.

Section 5: Key enablers to collecting Global Employee Disability Data

Exploring the building blocks that have enable global organisations to make progress.

The research report is created based on the experiences and opinions that Global D&I Leads shared and the respondents were predominantly BDF Partners and Global Taskforce Members. They are by definition “the converted” and so the findings in this report should be viewed in that light. However, the respondents were open about their less positive experiences, and there was a strong and consistent theme about the complexities inherent in this type of data collection.

The aim of this report is to be open, honest and transparent about those real and perceived barriers, and to highlight practical ways that global organisations have been able to overcome them.

The findings provide an excellent context for global organisations who are already engaged with this agenda to benchmark their progress and take the next steps on their data monitoring journey.

The research focused on collecting Global Employee Disability Data from an organisation's perspective. While the subject of the employee's experience of data collection came up numerous times, demonstrating the importance of the employee perspective, the full exploration of this was not undertaken as part of the research.

As this is a global report, we have used the terminology "people with disabilities" rather than "disabled people". Whilst "disabled people" is the preferred term in the UK and reflects the social model of disability, "people with disabilities" is the most widely recognised term globally.

1 Why do organisations collect Global Employee Disability Data?

Introduction

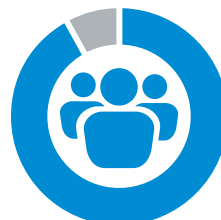
This section explores the motivations and drivers for global organisations to collect employee disability data. This question has been explored by all three research methods: group discussions, depth interviews and an online survey.

Given the challenges and complexities associated with collecting Global Employee Disability Data, we begin with the obvious question: why? Data of this type has the potential to provide interesting insights but arguably it achieves little by itself. Most of the research respondents were able to identify one or more reasons for collecting this data and these 'ultimate goals' informed their approach

Here we explore the most frequently occurring reasons, grouped under the headings: counting, improving the workplace and generating insights.

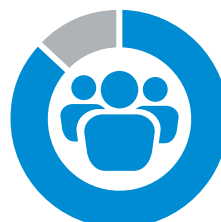
89%

"To advance the inclusive culture of our organisation".



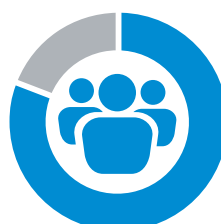
86%

"To understand how many employees have a disability".



84%

"To encourage more employees to share that they have a disability".



Counting

The most elementary reason for data global collection is to understand the composition of the current workforce and 'how many' employees have a disability. 86% of survey respondents named this as a reason for undertaking a global data collection exercise. However, often this related to the fulfilment of a bigger objective:

Representation: using the data to benchmark how representative their workforce is of the composition of wider society / industry sector / profession.

Compliance: using the data to evidence compliance with:

- External legal or regulatory targets or quotas (38% of survey respondents)
- Internal targets or reporting requirements (57% of survey respondents)

Sharing: using the data to encourage greater awareness and sharing internally or externally.

These objectives represent a number of important organisational concerns. The need to meet legal and regulatory requirements, and to be able to set and measure progress against internal targets, were all named by research respondents. One respondent mentioned the anticipated introduction of disability pay gap reporting in the UK and their intention to be prepared for what may be legally required. Often, these requirements were the catalyst for beginning to collect employee disability data.

“I would like [to say] that we do it to advance the inclusive culture of our organisation but, so far, it's mainly done for legal reporting purposes.”

Source: Research participant.

In these instances, the type and format of data collected was (at least to some extent) dictated by the requirement itself. For example, if data is being collected to meet a legal quota, the definition of disability used, and the timing and frequency of reporting are all likely to be fixed by the country/jurisdiction imposing the quota. Just over 100 countries around the world currently provide for employment quotas in their national legislation [1]. Likewise, if data is being collected in order to externally benchmark, it may need to reflect a country or regional census, or otherwise commonly used, definition.

In many cases, it was sufficient for this data to be collected on an anonymous, non-attributable basis, because it is simply about 'counting'. However, the country/regional variations on what needs to be 'counted', often made it difficult to roll the data together, to create a consistent global picture. We will return to the topic of data format in section 2 of this report.

Some respondents raised the issue that disability is often misunderstood or not a priority in the wider diversity agenda within global organisations. It was believed that self-I.D., and the resultant data, could raise awareness and keep the disability agenda 'front and centre'. Particularly amongst organisations who are data-driven, D&I Leads reported the challenges of making the 'business case', influencing leadership or getting wider buy in to disability inclusion initiatives, without any data to back up their action.

'Self-ID' is the process by which employees are invited to share how they identify themselves, commonly on the basis of demographic characteristics. In the case of disability, the employee is typically provided with a definition of disability and asked to share whether they identify as having a disability on the basis of that definition.

1 https://www.ilo.org/global/topics/disability-and-work/WCMS_735531/lang-en/index.htm

Improving the workplace

The second group of reasons for undertaking global disability data collection, are all related to the intention of improving the working lives of people with disabilities. This could be a practical improvement, such as a workplace adjustment, a policy improvement, or a cultural improvement, as follows:

Workplace adjustments: to understand scale, cost and specifics of adjustment requirements.

Organisational improvement: to understand how to improve or change policies / processes / accessibility.

Inclusive Culture: to provide people with the opportunity to share information about their disability with their employer, in the belief that self-I.D. is positively correlated with an inclusive culture.

// **We want to ensure that every individual can fulfil their potential, so we want to identify and remove any barriers that exist for employees with disabilities."**

Liz Douglas, Head of HR - Corporate Functions and Inclusion and Diversity at Anglo American.

Some of these reasons are about practical, tangible upgrades to enabling work, and removing barriers for employees with disabilities. They require more comprehensive approaches to data collection than 'counting' alone. Detailed information may be required, for example, in the case of understanding workplace adjustment requirements. Also, in the case of policy and process improvements, experiential and opinion data would be needed to fully understand any issues and how they could be rectified.

It was believed by some respondents, that this information enabled them to be targeted and smart with their disability inclusion strategy, because it unveiled tangible barriers or requirements that needed to be addressed.

// **Without data, you don't know where to act and how to prioritise your budget and initiatives."**

Research participant.

In the case of inclusive culture, there is a bigger prize, with all employees potentially benefitting from a more inclusive working environment.

89% of the survey respondents identified that their global disability data collection exercise had the intention of advancing the inclusive culture of their organisation. This is based on the premise that employees are more likely to share that they have a disability when they perceive the culture of their organisation to be inclusive. Likewise, the belief that the more employees who share their disability, the more this improves organisational culture, creating a virtuous circle of “it’s okay to say”.

Creating a workplace culture that is inclusive of employees with disabilities is a vital aspiration, but it is important not to assume that a high rate of sharing automatically indicates an inclusive workplace. Likewise, a low rate of sharing does not automatically mean a non-inclusive workplace: for example, cultural and religious beliefs and wanting to maintain privacy are all reasons why people may not share that they have a disability. This is particularly true in the context of global organisations, with many regional variations in culture. It may also be that if an organisation is inclusive, flexible and accessible already, then employees may not see the purpose of providing self-I.D. data.

“...it’s hard to know what self-ID and adjustment data is really successful at proving.”

Research participant.

Generating insights

The final group of reasons for undertaking global disability data collection are related to the creation of insights. Sometimes these insights were sought with the broad intention of using them to positively affect the organisation's inclusive culture. Sometimes the intention was to specifically hear about the lived experiences of employees with disabilities.

The three main reasons were:

Insight: uncovering people's stories and lived experiences.

Enablement: understanding what employees need to perform and thrive.

Talent Management: clarity of the advancement opportunities for people with disabilities.

// To build an inclusive work environment is an important priority for us at Accenture. To enable this to the fullest, we need to understand the unique needs of every individual. These insights will in turn help us in building the culture that can support and nurture the growth of every individual."

Vani Seshadi, Global Program Lead for Disability Inclusion and Cross Cultural Diversity, Accenture.

Research participants expressed a genuine and ongoing desire to understand the experiences of employees with disabilities, how these might differ from employees without disabilities and how they differ between their markets of operation globally. Almost 50% of survey respondents named these as reasons for a data collection exercise.

Organisations also wanted to understand their potential talent, given that people with disabilities are a significant talent pool, both within and outside their organisations. One survey respondent stated that disability data was collected to inform career development programmes specifically targeting employees with disabilities. Other research participants reported tracking diverse characteristics, including disability, through their whole people management processes: recruitment, promotion, appraisal etc.

“Disability data is not about the ‘have to do’, it is about the ‘could do’. Disability data would help us understand our untapped talent and consider our future talent attraction strategy.”

Julia Munday, Global Head of Employee Relations and People Operations at AMS.

Why not?

Where organisations were not collecting any global disability data, we asked them ‘why not’? The most commonly occurring responses were all related to the logistics or practicalities of data collection:



33% said “We do not have a system to request or store the data”.



22% said “We do not have a consistent global definition of disability, which prohibits consistent global reporting”.



22% said “We do not know if it is lawful to do so in the jurisdictions in which we operate”.

Of those organisations who currently do not collect Global Employee Disability Data, 44% said that it was their intention to do so within the next 18 months. This demonstrates the belief in the validity of Global Employee Disability Data collection and the commitment to overcoming the current barriers. We will return to the topic of organisational challenges in section 4 of this report.

Summary and Insights



Global organisations collect or aspire to collect global employee disability data for a range of reasons, from legal compliance to talent maximisation.



Organisations should carefully consider how they will use the data they are collecting, to improve the working lives of people with disabilities.



It can help to start with the end in mind. Agree the ultimate intention about global workplace disability inclusion and 'work back' from that aim, considering what global data collection can provide.



Organisations can then identify their data requirements to support that goal. These will include the necessity to comply with legal obligations but should also include more aspirational aims around improving organisational culture and the enablement of employees with disabilities.

HSBC case study

HSBC wanted to promote the message that collecting data was a good starting point for disability inclusion. HSBC would use the data to create clarity and insights for their senior leadership. HSBC's intention was to get more actionable data beyond pure representation. A question was added to their employee survey about whether people needed workplace adjustments and if employees were satisfied with the provision of workplace adjustments. This allowed HSBC to establish a clear process for why they should be collecting data.

2 : What Global Employee Disability Data do organisations collect?

Introduction

In this section we explore what data global organisations collect; we particularly focus on the standardisation of data, the type of data and definitions of disability used.

For many organisations the data they were collecting was connected to, and sometimes dictated by, the purpose of the data exercise.

Standardisation of data

A strong theme in the research was that global organisations want to create a global point-in-time snapshot of consistent data insights about their workforce. This intention drives the standardisation of data collection, both in terms of the type of data and the definitions/language used within that data collection.

When asked in the survey about the standardisation of data collection, the responses were as follows:

43%

"Yes, a standardised set of data is collected in some locations where we operate, where this is lawful".



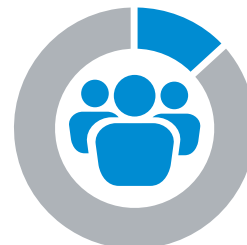
24%

"Yes, a standardised set of data is collected in all locations where we operate, where this is lawful".



14%

"No data is collected at all".



Almost a quarter of survey respondents had succeeded in creating a standardised global data set, specifically related to employee disability, and running data collection exercises in all the locations where this was lawful.

Other respondents used a range of data collection approaches, depending on the regional context. For example, this might mean requesting voluntary self-I.D. of disability in countries where collecting disability data is a legal requirement, but not collecting any data in countries where it is not a legal requirement, or it is unlawful. Organisations might still define this as a 'standardised' approach, because they have defined a set of parameters that they are following consistently, globally.

// We might collate data in a particular form and manner to meet the local legal requirements."

Research participant.

Of course, all global organisations have to act within the constraints of the legislation in their jurisdictions of operation. This makes it unlikely that any global organisation will be able to achieve a 100% data collection rate, because there are countries where it is not lawful to collect disability data and countries where the data can be lawfully requested, but requiring employees to share their disability with their employer cannot be mandated. So, for many organisations, the aim is to collect data where it is legally permissible and culturally acceptable to do so and to gain consistency, where possible, across those jurisdictions.

Some organisations had begun collecting data in one or a few of their operating locations, in order to pilot an approach that they intended to roll out globally. In their descriptions of their approaches, there is an element of not allowing the potential size of the task globally, deter them from beginning somewhere, locally. So, they may have started in a country where collecting data is relatively non-contentious, such as the UK, with the intention of building out from there.

// As Accenture follows the United Nations definition of disability, we intended to ensure that this is reflected in our self-declaration survey to help people better understand the value of declaration.

Hence in 2019, we started using the Washington Group questions and in the following year used the International Classification of Functioning, Disability and Health of the World Health Organization to elicit and record information on the functioning areas and disability of an individual. The survey ran for a month supported by internal marketing and communication campaigns in video, email, article, and blog formats. Engagement champions were also tapped and leads were given information on how to discuss the survey during meetings and town halls. From less than 1% prior the use of the WG and ICF, Accenture in the Philippines has achieved an above 4% declaration in its most recent survey.”

Gitanjali Krishnan, Global Inclusion & Diversity General Manager at Accenture, Philippines.

Definition of disability

In order to standardise a global data collection exercise, many organisations talked about the need to establish a globally acceptable and resonant definition of disability. This was one of the most frequently discussed barriers to being able to conduct a meaningful, global exercise, because of the significant variation in legal definitions and culturally appropriate language, globally.

Even the question of how and by whom the language is defined, presented organisational challenges. Should it be defined by global D&I Leads, who have diversity expertise, or locally by HR teams, who have the expertise in-country? Should the language used in local legislation be adopted, or should global/local disability ERGs help to shape the definition, on the basis of what is most resonant and respectful?

HSBC case study

HSBC created an inclusive language and imagery guide setting out a global definition for disability at the bank, together with globally relevant disability inclusive terminology as well as language dos and don'ts. The development of the guide was informed by feedback from colleagues with a disability, Diversity and Inclusion leads from various locations, and also external NGOs. HSBC recognises that in some countries there are different definitions for disability that are enshrined in local legislation or policy frameworks, and in these cases local Diversity and Inclusion leads have the option of editing the guides to incorporate country-specific terminology. The guides have been well received by the regions and have been translated into at least five languages.

The following responses from the online survey research, demonstrate the range of approaches used when defining disability for the purposes of data collection:



54% The legal definition within the jurisdiction you are collecting data



46% The definition used in the United Nations' Convention on the Rights of Persons with Disabilities



11% Your own organisation's global definition



9% Your own organisation's local definition, in each jurisdiction you are collecting data

Other definitions that were given in the survey responses were:

- World Health Organisation definition
- Do you consider yourself to have a disability or long-term condition? (Yes / No / Prefer not to say)
- Do you have a mental health condition, long-term health condition or disability? (Yes / No / Prefer not to say)

All of these definitions could be used for self-I.D. of disability, with some respondents explaining that they used this one question globally, where lawful, to create their worldwide 'snapshot'. Additional types of data might then be requested on a localised basis.

UN Convention definition of disability: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

WHO definition of disability: Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.

Washington Group questions: The Washington Group Short Set consists of the following six questions that ask about the degree of difficulty in doing activities in six basic functioning domains.

- 1. Do you have difficulty seeing, even if wearing glasses?**
- 2. Do you have difficulty hearing, even if using a hearing aid?**
- 3. Do you have difficulty walking or climbing steps?**
- 4. Do you have difficulty remembering or concentrating?**
- 5. Do you have difficulty (with self-care such as) washing all over or dressing?**
- 6. Using your usual language, do you have difficulty communicating (for example understanding or being understood by others)?**

Each question has four response categories, which are read after each question.

- 1. No, no difficulty**
- 2. Yes, some difficulty**
- 3. Yes, a lot of difficulty**
- 4. Cannot do it at all**

// Freshfields had identified that, apart from continually working to build a culture of trust and openness, one of the key challenges to collecting employee disability data, is establishing globally appropriate terminology. Freshfields have developed a global definition, with the support of Business Disability Forum that draws on the United Nations definition. From there, Freshfields have run a number of training sessions to promote a better understanding of the breadth of disability across the firm and will continue to build on this.

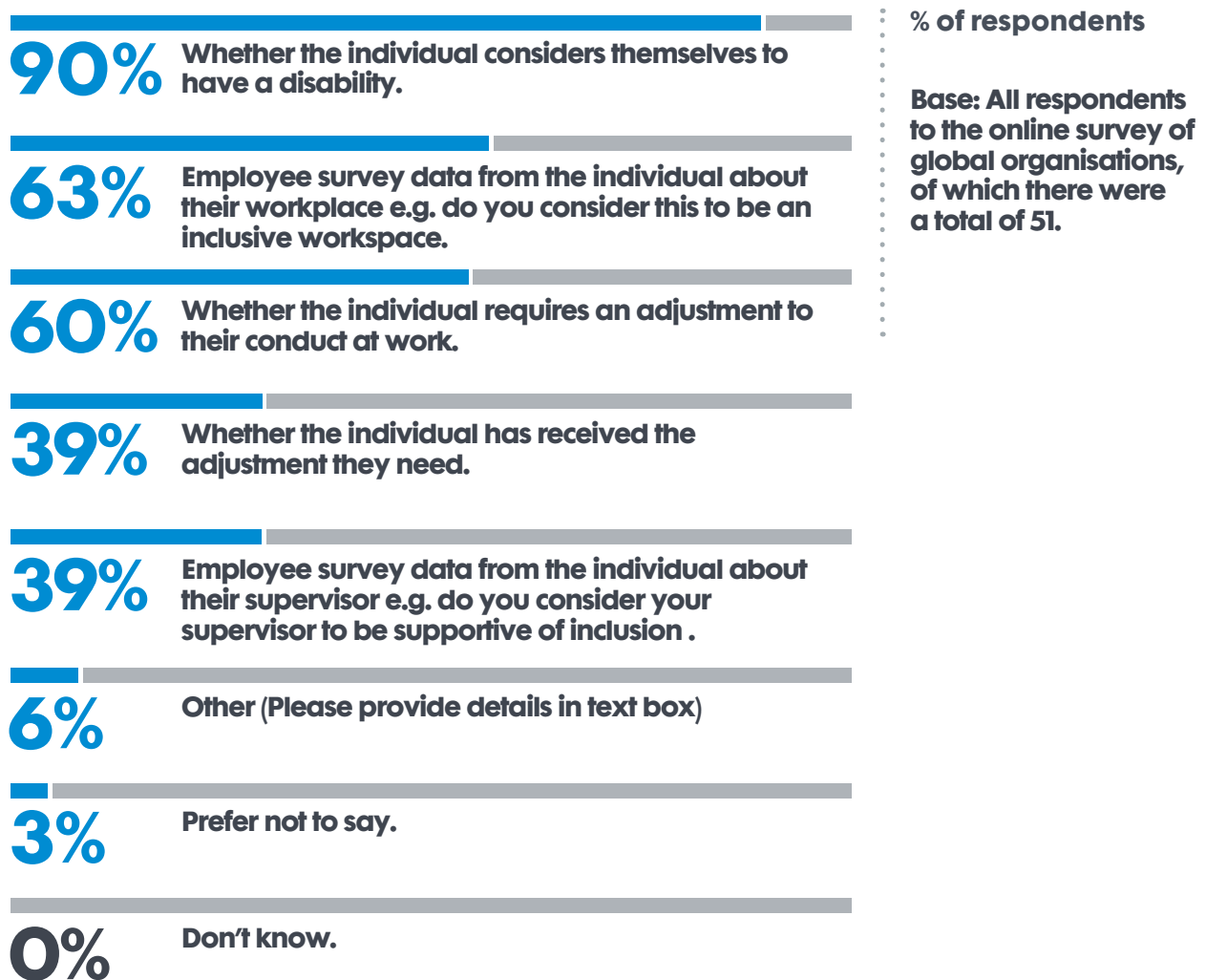
They are also in the process of defining a set of disability-related questions, which are locally relevant but also consistent across all jurisdictions to enable better global data collection.”

Kristina Adey-Davies, Global Diversity and Inclusion Senior Manager, Freshfields Bruckhaus Deringer LLP.

Types of data collected

The types of data that are legally required (for example, to evidence compliance with a quota) and the types of data that are lawful/unlawful, predictably had a significant impact on the types of data collected. The following responses from the survey demonstrate the main types of data collected by global organisations:

What data are you collecting?



The most frequently collected data type is self-I.D. of disability e.g. whether or not the individual identifies as an employee with disabilities. Some respondents reported that it was legally required in some of their jurisdictions to request additional information, such as what kind of disability an employee has and whether they have a certificate of disability. In some countries, very detailed information about disability was legally required and in others details from official disability-related documents were recorded.

Over 60% of responding organisations who collect Global Employee Disability Data, ask whether their employees require a workplace adjustment and nearly 40% also ask whether they have received the adjustment they need. Some organisations enquire about how satisfied an employee is with any adjustment they have received. These questions are sometimes asked on an anonymous basis, as a proxy for self-I.D. of disability and a performance measure of the adjustments process. Or they are asked on an attributable basis, as part of a workplace adjustment process, and the data may then be 'borrowed' for global disability reporting purposes.

We will return to the topic of how data is collected in section 3 of this report.

Summary and Insights

- ✓ Many global organisations aspire to collect a standardised set of employee data, using a globally resonant definition of disability. The challenges of achieving this are explored further in section 4.
- ✓ Respondents typically used either the United Nations definition of disability, the World Health Organisation definition of disability, or their own global definition, when providing employees with the option of sharing their disability status (where lawful).
- ✓ Legal definitions and terminology remain a strong determinant of the language used, and the type(s) of data collected, where the driver of data collection was predominantly about legal and quota compliance.
- ✓ Workplace adjustment data and employee opinion data was also collected by global organisations, which provides more insightful and actionable data, to improve the working lives of people with disabilities.
- ✓ While legal compliance is necessary for global organisations, where these legalities aren't in place, it is important to carefully consider the data you are requesting and why. It should not be assumed that more is better, if nothing purposeful is achieved with the collected data.
- ✓ Organisations could consider 'Glocalising' their approach. One size will not fit all in a global data collection exercise; there will always be regional variations and requirements. So, a global aspiration and baseline data standard may be set, but that could be applied with local adaptations.
- ✓ Organisations could consider the development of a disability scorecard, which could bring together multiple types and forms of employee disability data, which may already be collected across different departments, including:
 - disability 'count'
 - disability quota compliance
 - level of self-ID
 - adjustment requests
 - adjustment response times
 - disability inclusion from employee surveys
 - qualitative opinion data from ERGs / champions / listening groups

3 : How do organisations collect Global Employee Disability Data?

Introduction

In this section we explore the approaches and tools used to collect Global Employee Disability Data.

The practicalities of data collection, storage and handling were frequently expressed as one of the significant barriers to getting started. Here we look at the collaboration required and the various channels of data collection that global organisations can use.

Collaboration

Global Employee Disability Data collection is an organisation-wide activity and requires collaboration across multiple departments. Human Resources, IT, Compliance and Legal departments are all concerned with the appropriate handling of (sensitive) employee data requests. Global D&I Leads spoke of the need to collaborate with other specialist departments, both to secure their help and to avoid their disability data efforts being derailed further down the line, when concerns later arose.

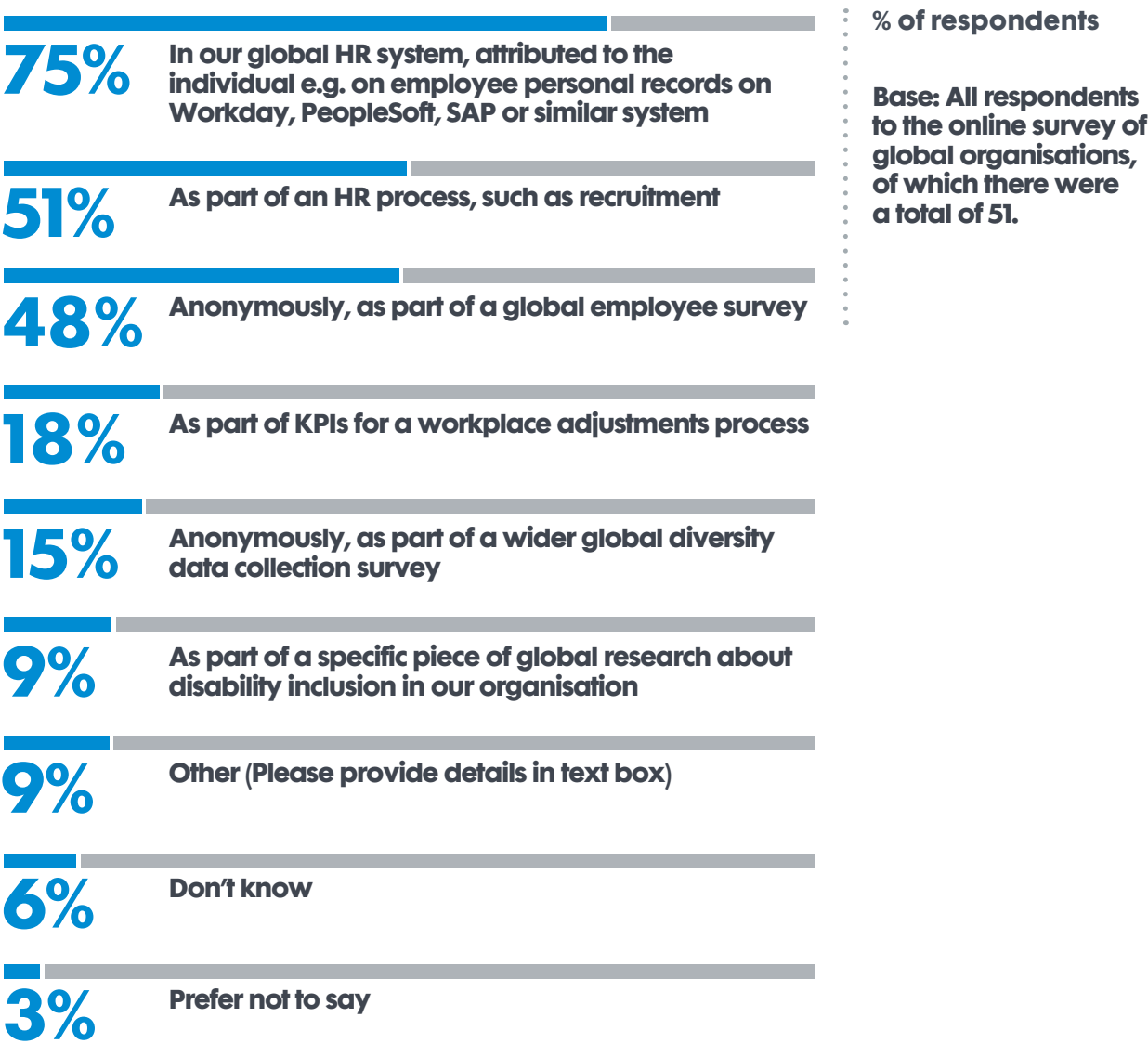
Some Global D&I Leads reported this necessary consultation as hugely time consuming; not least because their aspirations for data collection may be at odds with another department's concerns about the risks of data handling. Others reported that they would not have made the progress they have done, without this collaboration.

This cross-departmental collaboration is also important because it may be that many forms of employee disability data collection already exist within an organisation. Various functions may request this information to assist their work e.g. the IT department may ask about required adjustments, when they are setting up a new user. It is important not to duplicate these self-I.D. requests, unless it is unavoidable e.g. due to data protection, because multiple self-I.D. requests place an additional burden on people with disabilities.

Data channels

Due to the challenges global organisations face with collecting employee disability data, some organisations choose an existing or initial channel of data, to begin to make progress or to pilot an approach.

In answer to the question in the survey “how are you collecting data?”, the following responses were given:



The most frequently occurring data collection channel, was by self-I.D. in a global HRIS. One respondent highlighted the importance that employees should have ongoing access to the self-I.D. via a self-service portal, to enable them to update this information about themselves at any time.

Significantly, if disability data is requested and stored on an HRIS, it is attributable to the individual. This is helpful to organisations, because the information can be used to generate insights about the working experiences of employees with disabilities. For example, are employees with disabilities getting equal access to development programmes and promotions opportunities? However, the identifiable nature of this data also triggers risks and concerns for organisations, and individuals, about data security, privacy and access.

This risk is reduced if data is collected anonymously, for example via an anonymous employee survey. This is the data channel 15% of survey respondents reported using. We will return to the topic of anonymous vs attributable data in section 4 of this report.

52% of the survey respondents reported collecting disability data via their recruitment process (or other HR process). Collecting data in this way created a snapshot of the diversity of their candidates and insight into the potential barriers in their recruitment and selection pipeline.

Data collected this way may or may not then have been transferred onto an individual's employment record. Where data transfer was possible it is noted the classification system used within an HRIS must mirror that of the recruitment system used. Sometimes there may be no connectivity between the recruitment and HR/ payroll systems. In some jurisdictions there are legal reasons why this data cannot be automatically transferred.

Through discussions with the Working Group and the depth interviews, it was also apparent that the data channels may vary significantly across a global organisation. In the absence of a single HRIS that the organisation has implemented as its one 'source of truth', the reality was that various localised approaches were created, to meet the local data requirements.

Summary and Insights



The collection of Global Employee Disability Data is a collaborative exercise, with Global D&I Leads needing to invest significant time in liaising with multiple internal stakeholders.



These specialist stakeholders can be very helpful in establishing successful systems, in minimising the duplication of data and data requests, in ensuring data is captured in line with data privacy laws/regulations and risk associated with its intended use is identified and managed.



Global organisations use a range of approaches and tools to collect employee disability data, with the most frequently reported being a global HRIS.



It is helpful to begin by mapping the organisation's disability data requirements. Clarify the type(s) and form(s) of employee disability data that are required and match the collection approach to the goals.



Organisations can check their data assumptions, by discussing the intended data collection intentions and approaches with their employees with disabilities.

4 : Key challenges to collecting Global Employee Disability Data

Introduction

In this section we explore the challenges and barriers global organisations commonly encounter, or anticipate they will encounter, when navigating employee disability data collection.

It was apparent through the Working Group discussions, depth interviews and survey responses that the challenges were many, varied, and highly complex. The intention of exposing these barriers, is to help organisations who may be beginning to collect data, to anticipate and resolve them in their approaches.

A spectrum of challenges

All research participants identified substantial challenges that they had experienced, or were anticipating, with Global Employee Disability Data collection. The survey respondents were able to select more than one response to the question “What is your most significant challenge with collecting Global Employee Disability Data?” and the most frequently selected were:



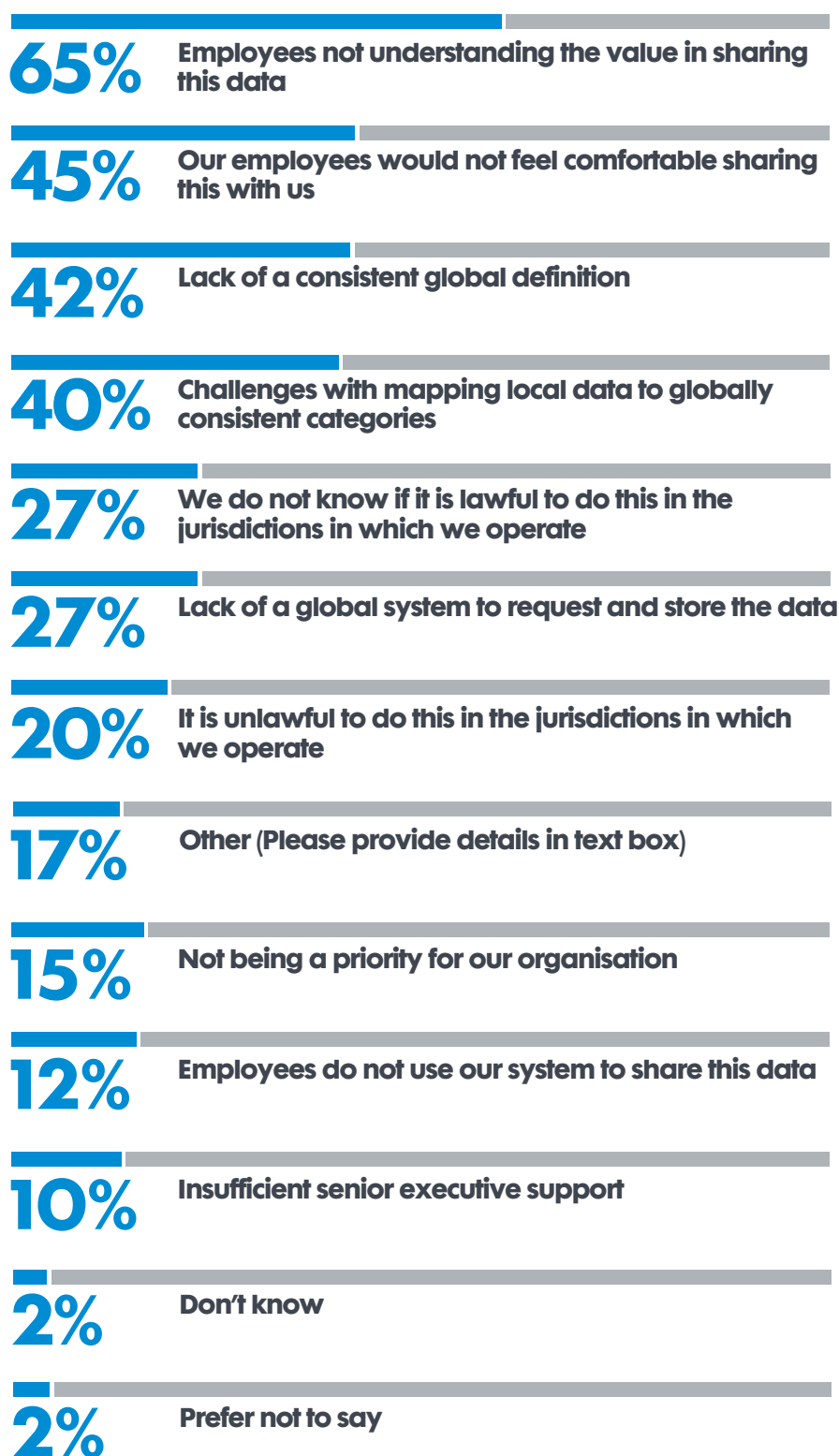
65% Employees not understanding the value in sharing this data



45% Our employees would not feel comfortable sharing this with us



43% Lack of a consistent global definition



% of respondents

Base: All respondents to the online survey of global organisations, of which there were a total of 51.

It is significant that the two most frequently selected responses from the survey pertained to individual employee attitudes or beliefs. This is a reminder that amongst all the organisational issues that Global D&I Leads have to navigate, and which a lot of the research discussions focused on, the final decision about whether or not to self-I.D. will be made by the individual.

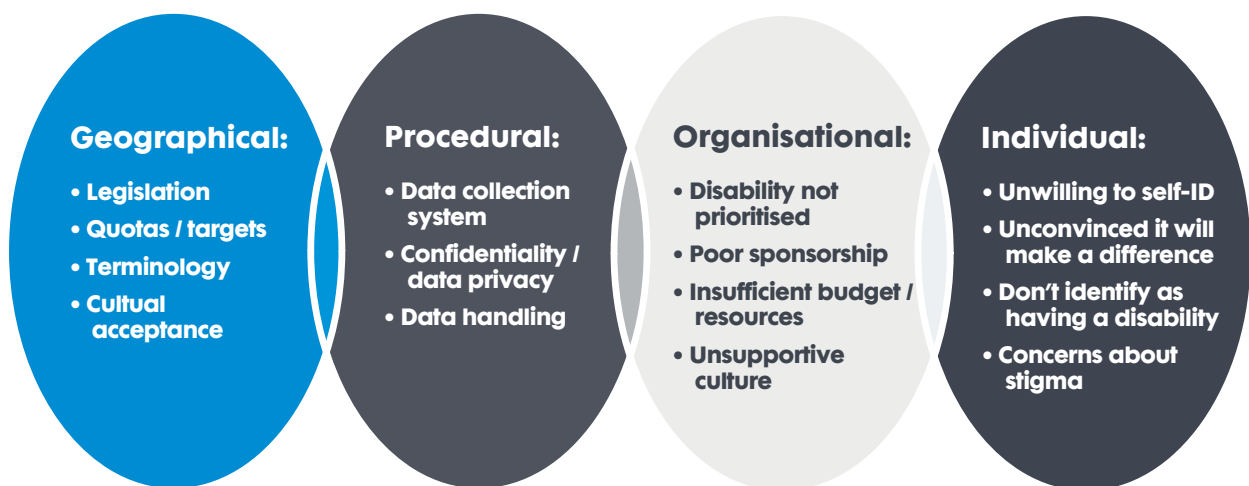
The survey respondents also identified the recurring organisational issue about a lack of a consistent global definition, which we discussed in section 2 of this report. Some provided a simpler response of their own:

// We don't know how to do it."

Research participant.

Combining all the research sources together, four clusters of challenges emerged, each of which needs to be considered by any global organisation.

We explain and discuss the four clusters below: geographical; procedural; organisational; individual.



Geographical

- **Legislation:** legislative differences and definitions make a single, global approach near impossible for many global companies. Some of the organisations who participated in the research have invested significantly in accurately mapping what disability data must be / could be / cannot be collected, in their various jurisdictions of operation. Over 27% of survey respondents named not knowing whether it was lawful to request disability self-I.D. in their jurisdictions as a significant challenge. For some organisations, their countries of operation with older and more embedded equalities legislation have been easier to navigate, because there is greater clarity about disability terminology, protections and inclusions in the legislation.

// There will always be different challenges in different contexts, but legalities should not be used as an excuse to not make progress; we have to consider what we CAN do, and stop thinking it is too hard or only engage if it is all or nothing."

Fatima Choudrey, Associate Director, Global D&I Strategic Operations and Head of D&I EMEA, at Baker McKenzie

- **Quotas/Targets:** for global organisations with a presence in one or more countries that mandate disability quotas, complying with those requirements is a necessary priority. The challenge this causes for Global D&I Leads, is deciding how to reconcile the potential differences across in-country quota requirements, in order to 'roll them up' to create an organisation-wide target. Alternatively, organisations may decide to take a country-by-country approach, using the legal quota or other relevant contextual benchmark (such as census data) to consider their representation of people with disabilities in-country only.

Quota: the number/proportion of people with disabilities that an organisation is mandated by law to employ.

Target: the number/proportion of people with disabilities that an organisation voluntarily defines for itself that it aims to employ.

- **Terminology:** the lack of a translatable worldwide definition, which enables organisations to collect globally applicable and locally resonant data, was identified again as a challenge. 40% of survey respondents named challenges with mapping local data to globally consistent categories, as a key barrier for them. In addition to that, there is a difficulty for employees responding to a self-I.D. request, in their understanding of what is being asked. The terminology applied globally may be less recognisable in-country, and may even cause offence, leading employees to respond inaccurately or opt out of self-I.D.
- **Cultural Acceptance:** globally, some locations were reported as being more challenging to request and collect employee disability data, because disability and mental health have some form of stigma attached to them. There are cultural differences across multiple countries, which may make it difficult or inappropriate to request self-I.D., which a data collection exercise being led 'from the centre' may not appreciate.

It is important to acknowledge that all of these considerations would also apply to a single-country data collection exercise; legislated quotas, terminology and acceptability are all vital to get right at the country level. The additional challenge of these considerations at the global level are about the complexity and inconsistency created by the requirements in multiple jurisdictions and thus, the difficulty of establishing a single approach.

Procedural

- **Data collection system:** research participants experienced significant issues with global HRIS format and functionality, in the pursuit of conducting a global disability data collection exercise. They needed a global definition of disability and any additional global disability data categories to be built into the system. They also needed the system to be agile enough to accommodate the requirements and terminology of local jurisdictions; if additional/different in-country data was required, the system needed to be able to drop down to that level of detail. Even where a well-configured global HRIS existed, integration with other relevant systems or tools was also a challenge. This could be a recruitment system, payroll system or a workplace adjustments system, where the same or similar disability data was also being requested and stored.

For some organisations, and for over 27% of the survey respondents, a global HRIS did not exist. This meant that every location had their own vehicle for disability data collection and storage (or none), such as using Excel spreadsheets. This made the collation of a global 'view' of employee disability data both time-consuming and inaccurate.

A Human Resources Information System (HRIS) is a software or online solution that is used for data entry, data tracking and the data information requirements of an organisation's human resources (HR).

- **Confidentiality / data privacy:** depth interview participants and the Working Group identified challenges with data confidentiality, anonymity, and privacy. Understanding and being clear with employees about the difference between anonymity and confidentiality, was key. Also, being clear about what the data is being requested for, which in turn gives the organisation permission to use it for that purpose (only).

Data confidentiality: where data is attributable to an individual or they might be identifiable from it, data confidentiality seeks to safeguard that information from being compromised and puts in place measures to ensure it is only accessible by authorised parties.

Data anonymity: data that is not attributed to an individual (the 'data subject' is removed) and individuals are not identifiable from it.

Data privacy: an element of data security that is concerned with the proper handling of personal data, such as the rights of an individual to have access, accuracy and erasure of data held about them.

Data privacy was very challenging for global D&I Leads. The legislation governing data privacy and data processing is complex and varies across the world.

The legalities needed to be understood and then decisions needed to be made about who has access to the data and what the data will be used for when they access it. Some participants shared their expectation that if employees knew that HR colleagues and line managers could see their disability data, it could be a deterrent for them to self-I.D. Aggregating data in a way that still maintained employee confidentiality was another challenge: how could employee disability data be reported, particularly from small offices or departments, so that individuals aren't identifiable? Global D&I Leads also shared that they have been challenged by internal data privacy experts, on how much they really need to know about individuals' disabilities.

// Globally, data privacy legislation and compliance differ significantly by country, so companies have to be flexible across the markets that they operate in."

Manisha Mehta, Global Diversity & Inclusion Manager, Unilever.

// Data privacy is very challenging: who can see this information, and how do we keep it up to date and accurate? We have liaised with our in-country Legal teams for advice, which has really helped."

Lizelle Caballes, Talent Excellence Advisor, Shell.

- **Data handling (warehousing / transference):** lastly, global D&I Leads shared challenges of bringing together confidential data from various global sources, either via data warehousing or transferring data across jurisdictions. Again, some had worked through the practicalities and legalities by liaising with internal experts, reinforcing the need for collaboration across departments.

Organisational

- **Disability (data collection) not prioritised:** For some organisation, other diversity characteristics, such as gender and ethnicity, were prioritised above disability. Various factors drove the prioritisation of other characteristics, such as gender pay gap reporting in the UK, or simply the availability of data. 15% of survey respondents named a lack of prioritisation as a barrier, however, it is important to note that their responses were about prioritising collecting employee disability data, not about prioritising employees with disabilities.
- **Poor sponsorship:** 10% of survey respondents named insufficient senior executive support as a barrier to being able to collect global disability data. As above, this may not mean that there is a lack of senior support for disability inclusion in the workplace, it may simply be that data collection specifically is not supported as an important contributing factor to that.
- **Insufficient budget/resources:** some global organisations reported not having a designated Global D&I team, or even Global D&I Lead, so their D&I strategy and initiatives were constrained by lack of resource, expertise and low budget. The impact of this on Global Employee Disability Data collection is that there may be no-one centrally to lead and co-ordinate the approach, and/or no means by which to prioritise the initiative, particularly given its known complexity.
- **Unsupportive culture:** the importance of a 'supportive culture' came up regularly in the Working Group discussions and depth interview. So, in contrast, the absence of a supportive culture was identified as a significant barrier to Global Employee Disability Data collection. This may be characterised by a lack of inclusive culture or commitment to diversity more broadly or may specifically pertain to a culture that is unsupportive of disability.

Individual

- **Unwilling to share:** 45% of survey respondents named employees not feeling comfortable to share as a significant barrier to global data collection. This unwillingness could be about individual privacy preferences, could relate to an individual's culture or belief system, or could pertain to negative experiences the individual has had previously e.g. at a previous employer.

Employee unwillingness could also be about the point in time. For example, if an organisation is going through a restructure or is struggling financially, an employee with a disability may feel more vulnerable as a result. This raises the issue of employer clarity and employee trust; in why the organisation is asking for disability information, in what the employer will use the information for and whether the employee believes it could be used to their detriment in any way. The employee might wonder "what's in it for me?" and would certainly want to be confident that any perceived benefits would outweigh any perceived risks.

This unwillingness to share on the part of the employee could also stem from a number of other factors that research participants shared:

- **Being unconvinced it will make a difference:** 65% of survey respondents believed that their employees would not understand the value in sharing this data. Some participants hypothesised that this could be about the employee not believing that appropriate action will be taken as a result. Some global organisations shared that the absence of a procedure or plan, as to what will happen once employees had shared disability data, was a valid reason for them not collecting data in the first place.
- **Not identifying as having a disability:** some employees may not generally identify as having a disability or may not identify with the particular definition or terms used by the organisation. To overcome this, some organisations reported adopting a broad and inclusive definition of disability, or used workplace adjustment data as a proxy for disability self-I.D. instead.
- **Concern about stigma:** There is still a significant cultural barrier in many countries to speaking openly about disability and identifying as a person with disabilities. So global organisations are likely to need to take different approaches, use different language, and give different reassurances about anonymity/confidentiality, in their various global contexts.

As mentioned previously, these issues are not peculiar to global organisations; employees with disabilities in a UK-only company may also have these views. The additional complexity for a global organisation to navigate, is that there will likely be multiple variations, often mirroring the context and culture of the locality.

Summary and Insights



Through the research process, clear themes emerged about the challenges global organisations had experienced, or anticipated they would experience, with Global Employee Disability Data collection.



Many of the challenges discussed would also apply in a single-country approach, but the additional complexity in global data handling was due to the variation between countries and jurisdictions. These variations impacted every element of data collection, from the legal considerations to the in-country culture.



Research participants shared their frustrations about the amount of time, effort and money it had taken to navigate the legal considerations, system requirements and data handling constraints.



On top of that, the culture of the organisation and the individual willingness of employees to participate in self-I.D. should not be underestimated. If people don't know why you are collecting the information and what you are going to do with it, they might be reluctant to share, what is often considered very private, information.

Timing is important:

- For the organisation. For example, if an organisation is going through a restructure, an employee with a disability may feel more vulnerable, and less likely to share their data, as a result.
- For the individual. For example, they may be awaiting a diagnosis or not identify with a disability at the point in time.



Organisations need to foster a work environment where employees feel it is safe for them to self-I.D., where they know it won't be detrimental to them to do so and where they believe that something positive will happen as a result (if it needs to).



Global D&I Leads should involve their specialist colleagues from the beginning, so that the full spectrum of considerations is represented: legal (employment law and data privacy law), IT system constraints etc.



Consider and collaborate with any stakeholders who use data; important information about employee disability may already exist elsewhere.



Tailor the approach to the jurisdiction, including the terminology used, the definition in the appropriate language, the positioning of the request and communications that surround it.



Collaborate with the local HR/D&I Leads, who know the context and culture best.



Make it clear to employees what disability data is being requested for, who can access it and how it will be used.

5 : Key enablers to collecting Global Employee Disability Data

Introduction

In this final section, we look at key enablers for collecting Global Employee Disability Data.

Through the Working Group discussions, depth interviews and online survey, clear themes emerged about what had supported global organisations in getting started and building momentum. We explore four topics that form the 'building blocks' for success, which global organisations shared.

Key enablers

Amongst the responses to the online survey question "What has been the most significant enabler, which has helped with collecting Global Employee Disability Data?" two answers were most frequently selected:



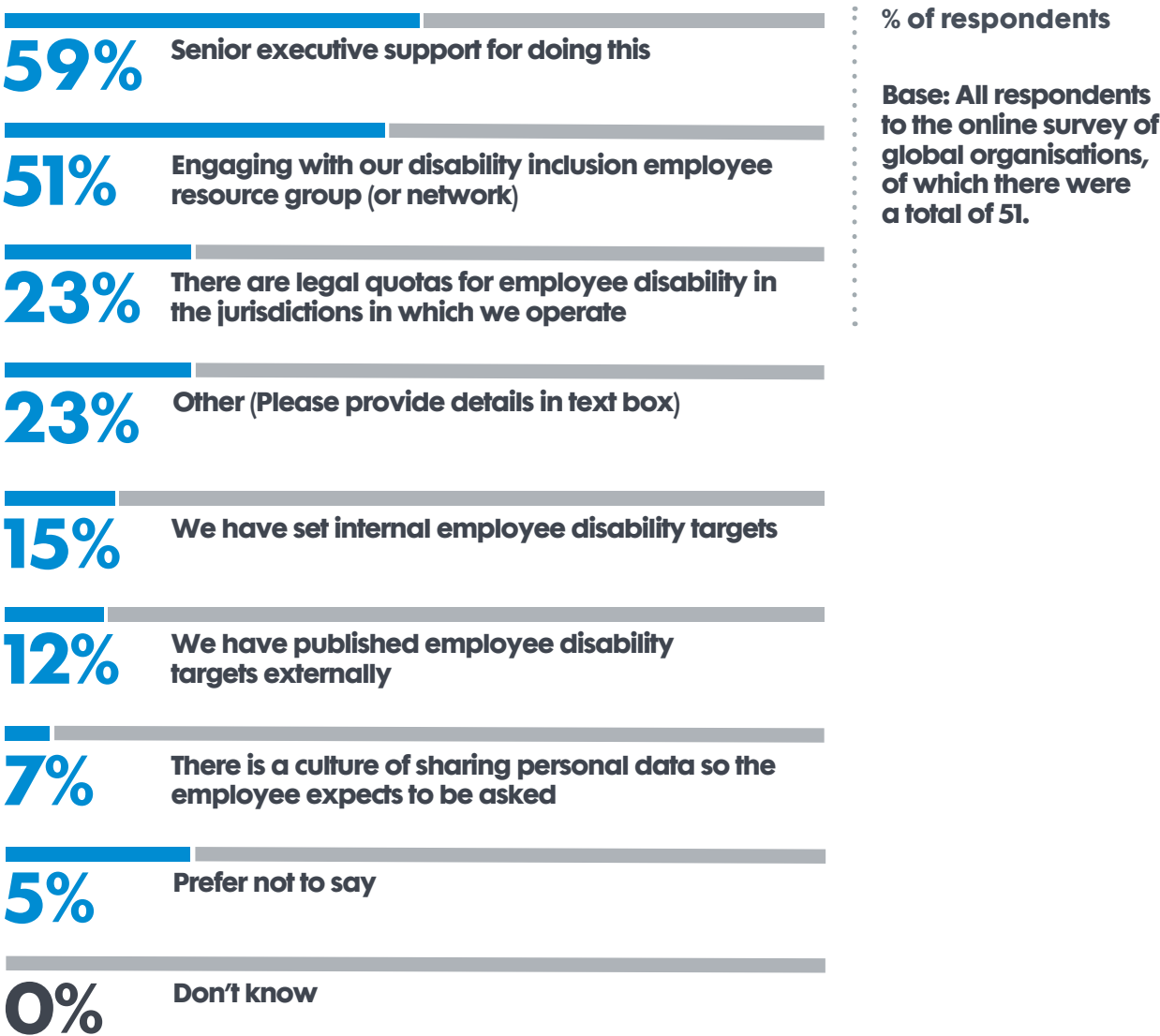
The strength of response about these enablers is significant, given how much discussion about Global Employee Disability Data often focus on legalities and systems. This is a recognition of the part that people play in the success of data exercises.

Some written survey responses demonstrated the range of factors that can play a part:

“Reassuring employees about how their data will be stored/used”

“Focussing on inclusion first”

“Increasing client demands”



Amongst the depth interviews and Working Group discussions, the wide range of enabling factors were discussed, and while these were broad, we have summarised them, below, into four 'building blocks' that can enable organisations in getting started and building momentum. We will discuss each of these in turn.

Purpose: A clear and compelling reason, or set of reasons, why Global Employee Disability Data collection is important, and what it is intended to achieve.

Fundamentals: The globally consistent and locally resonant terminology, systems and resources, which makes Global Employee Disability Data collection work.

Leadership: Sponsorship, role modelling and accountability at the most senior level(s), which positions disability inclusion as a 'call to action' that impacts everyone.

Culture: An organisational culture of psychological safety and trust, which enables employees to talk openly about disability and lived experience, without fear of detriment.

Purpose. A clear and compelling reason, or set of reasons, why Global Employee Disability Data collection is important, and what it is intended to achieve.

Global D&I Leads frequently expressed the importance of a clear purpose in disability data collection. The following were all identified as playing a part in global organisations' motivation and should be considered as a collection of enabling factors:

- **Compliance:** over 23% of survey respondents named legal quotas as an enabler, over 15% had set an internal employee disability target and nearly 13% had published their target externally. These organisations will not be able to track their progress towards, or compliance with, these commitments, without employee disability data.

// We are committed to having employees with disabilities representing 5% of our workforce by 2025."

Manisha Mehta, Global Diversity & Inclusion Manager, Unilever.

- **Good practice:** some global D&I Leads were conscious that other organisations were collecting employee data and acting on the information; they felt motivated to adopt good practice role modelled by other organisations and were concerned about 'falling behind' competitors.
- **Client expectations:** increasingly global D&I Leads were seeing expectations from clients about clear commitments to D&I. This expectation may have been accompanied with the request to see diversity data (including employee disability data), either as evidence of a commitment to diverse representation or as a proxy for inclusive culture.

// We have to see this as part of the wider inclusion agenda and connect it to our people priorities and commercial strategy; our clients care about diversity and inclusion too."

Fatima Choudrey, Associate Director, Global D&I Strategic Operations and Head of D&I EMEA, at Baker McKenzie

- **Disability inclusion:** the ultimate and overarching intention to improve the working lives of employees with disabilities.

Clarity of purpose filtered into a number of other enabling factors, such as creating a sense of urgency, providing clarity about what actually needed to be collected, and establishing the basis of communication and messaging that was needed from senior leaders. Establishing the purpose was described as the most important first step, without which much time and energy could be wasted.

Fundamentals. The globally consistent and locally resonant terminology, systems and resources, which makes Global Employee Disability Data collection work.

Having established clear purpose(s) for Global Employee Disability Data collection, the next building block of enablers was about getting the right practical tools in place. The following enablers typically arose:

- **Clarity and consistency:** agreeing a clear and consistent definition of disability and appropriate terminology and agreeing a global approach to what data will be collected and how. It is important to note that 'consistent' definitions and terminology does not always have to mean 'the same everywhere'. This is more about making sure that the language and approach adopted, consistently works towards the purpose of global data collection, even if that means local variations need to be applied.
- **Resources:** making sure the global and local D&I Leads have the capacity, resources, budget etc. to take the purpose into action. Some D&I Leads described the paradox that it was challenging to make the business case for the necessary resources, without the data to evidence the need.

- **System capability:** at the basic level, this was about having a secure and accessible system, which practically enabled the storage of employee self-I.D. data. At the more comprehensive level, Global D&I Leads aspired to a system that enabled the whole process of data collection and deployment: a global system that could be used to request, store, interrogate and report on employee disability data and that would trigger any additional processes, such as requests for workplace adjustments.

Reflecting back on the topics of discussion under section 4 of this report about key challenges, all of these fundamental enablers were named as challenges, if they were not in place.

Leadership. Sponsorship, role modelling and accountability at the most senior level(s), which positions disability inclusion as a 'call to action' that impacts everyone.

59% of survey respondents named 'senior executive support' as the key enabler for global employee data collection. In conversation with the Working Group members and the depth interviews, the components of that 'support' were extrapolated, as below:

- **Sponsorship by the CEO/Board/Leadership:** research participants raised the problem of disability not being part of (or not at the top of) the organisational diversity agenda, so this enabler was about explicit support from executives, for the prioritisation of disability inclusion initiatives. Disability needed to be actively called out as an important organisational agenda.

// At Unilever we have clear leadership support, without this it's very difficult to drive any cultural change."

Manisha Mehta, Global Diversity & Inclusion Manager, Unilever.

- **Leadership accountability:** global D&I Leads shared the traction that can be created by having an executive sponsor for disability, who would be accountable and lead the accountability of others. There should be a cascaded 'call to action', so that it is clear to leadership what they could and should do, to support disability inclusion.

// At Freshfields, leadership support is invaluable. Freshfields have a focus on the role everyone can play in practicing inclusive behaviours and allyship across the firm. However, the impact of leaders is pivotal in building on their approach. Their disability senior sponsors proactively get involved with the employee network, training sessions and in supporting individuals.

Having leaders who role model the importance of disability inclusion, authentically, and who are able to use respectful and inclusive language about disability is key. Disability inclusion has also been discussed at board level and very much continues to be on the leadership agenda which will with time encourage more understanding and openness and individuals both identifying with and sharing data on their disability.”

Kristina Adey-Davies, Global Diversity and Inclusion Senior Manager, Freshfields Bruckhaus Deringer LLP.

- **Clear and compelling communication:** communication from leadership, about the reasons for collecting disability data, the action that will be taken as a result and reassurances about what data will not be used for, enabled a request to self-I.D. disability to be positioned in an appropriate context. It ensured that a disability data request was not the first thing the organisation had communicated to its employees about disability.

// One of the biggest enablers has been the areas of the company who are already collecting employee disability data, talking openly about why this is beneficial. Senior leadership and support have also been significant.”

Lizelle Caballes, Talent Excellence Advisor, Shell.

- **Disability role modelling:** research participants were able to share how powerful it had been, to have disability positioned by leadership as something that impacts everyone. Some achieved this by leaders sharing their own lived experiences of disability, which gave permission for colleagues to share their own.

// Allianz has an employee disability network, which supports their disability inclusion agenda. The network facilitates numerous events for colleagues and they have had a webinar, which featured senior leaders sharing their non-visible disabilities and lived experiences. This role modelling is been important in creating the right culture.”

Amanda Armstrong, Operations Analyst, Allianz Insurance.

Some of these elements of leadership make a tangible contribution to the success of a global disability data collection approach. However, most importantly, they position disability inclusion as an organisational priority, and foster a culture of enablement.

Culture. An organisational culture of psychological safety and trust, which enables employees to talk openly about disability and lived experience, without fear of detriment.

The final building block to enable global employee data collection centres on organisational culture, which has the power to enable sharing and participation. The following elements were discussed with research participants:

- **Psychological safety and trust:** global D&I leads were very aware of the importance of an environment in which people feel comfortable to share and discuss disability. Where employees were able to be open about how a disability impacts their working life and lived experience, it was believed this correlated with higher self-I.D. rates and requests for workplace adjustments.
- **'Role modelling':** sometimes the global leadership of an organisation can feel far removed from the on the ground employee experience, so something global D&I Leads raised as an important enabler was visible role modelling, at all levels and at all locations. Connected to this was working closely with local D&I Leads, and leveraging their in-country knowledge and cultural insights, to foster a culture of disability inclusion everywhere.
- **ERG support:** 51% of survey respondents named 'engaging with our disability inclusion resource group or network' as a key enabler. The ERG participants provided 'ground up' support, insights and lived experience. Their preparedness to champion disability inclusion and be vocal advocates helped to open the dialogue for everyone and create a platform for people to share their stories. Also important was keeping ERGs in the 'data loop' on the self-I.D. of employee disability and the positive outcomes the data had contributed to. This kept encouraging their participation.

// It is an interesting idea when considering the anxiety that many people have about sharing information. If we get the things we focus on, and we focus on not sharing information, does that mean we get stuck in thinking we have some kind of secret when we have a disability or health condition?

// At PurpleSpace, we know that the more people with disabilities feel able to share information in formal and informal ways, the more able an organisation is to secure data that supports the case for change – in terms of pay, reward, progression etc. Of course, these things are not always easy to do and for some of us we need a supportive environment before we chose to share information in the same way as we do our nationality or marital status for example. But if we can get used to the idea of sharing information at work then we are more likely to help our employers build more confident systems to support people into work and stay there. This is a two-way deal. Employers need to earn the right to be entrusted with our personal information and as employees we have to play our part in the system before we can expect it to respond.

In our experience, high performing disability employee networks and resource groups are the primary vehicle for enabling employees with disabilities to feel good about themselves at work and build the confidence to share information about themselves with their colleagues and employer.”

Kate Nash OBE, Creator and CEO, PurpleSpace.

Summary and Insights

- ✓ Through the research process, clear themes emerged about what had supported global organisations in getting started and building momentum.
- ✓ It was important to establish the purpose: a clear and compelling reason, or set of reasons, why Global Employee Disability Data collection is important, and what it is intended to achieve.
- ✓ Organisations needed to get the fundamental in place: the globally consistent and locally resonant terminology, systems and resources, which makes Global Employee Disability Data collection work.
- ✓ Leadership support was vital: the sponsorship, role modelling and accountability at the most senior level(s), which positions disability inclusion as a 'call to action' that impacts everyone.
- ✓ The role of organisational culture should not be underestimated: a culture of psychological safety and trust will enable employees to talk openly about disability and lived experience, without fear of detriment.

Conclusions

This research has explored the key considerations for organisations, when collecting Global Employee Disability Data. Using a variety of inputs from global D&I Leads, it has surfaced commonly occurring factors that global organisations have experienced, are experiencing or anticipate experiencing, in their approach.

One of the most important factors to consider is the purpose of collecting data: what is the organisation trying to achieve and how will data support that aim? Creating that clarity from the outset will then guide the specifics of data collection and inform the most appropriate approach. Above all of the legislative and compliance requirements for gathering Global Employee Disability Data, global D&I Leads repeatedly expressed an overarching motivation to foster disability inclusion in their organisations and to improve the working lives of people with disabilities.

Once this purpose is established, Global D&I Leads have the complexity of global and local legislation, quotas, language and culture to navigate; all of these factors impacted what data they would actually collect. They also have to consider how Global Employee Disability Data can be collected; the systems that may be required and the way the data can be stored, interpreted and reported. It was evident from the experiences of global D&I Leads that early collaboration with other specialists within their organisations, such as Legal, Compliance, IT and Data Privacy teams, had helped enormously. Local, in-country D&I Leads or HR teams were also part of the collaboration, as they knew the culture and context better than anyone in 'head office'.

Whilst all the organisations we spoke to could identify multiple barriers to being able to successfully collect Global Employee Disability Data, the majority did not let that put them off beginning the exercise somewhere and somehow. Many used this partial exercise of starting to collect data as a testing ground, to pilot approaches that over time could be adopted more widely.

It became clear that global organisations needed to be prepared to flex their approach to each context; rather than getting hung up on creating a 'pure' data exercise, they needed to keep the ultimate goal - of improving the working lives of people with disabilities - in mind.

Despite all the challenges research participants were able to identify, they also spoke comprehensively about the many enablers they had experienced, to getting started with global disability data collection. These included the clarity of purpose spoken about above, and the logistics of the exercise, and also included the vital role of leadership and organisational culture. Leaders who were accountable role models and who positioned disability as something that impacts everyone, were able to set the organisational tone about disability inclusion. They had an important part to play in creating a psychologically safe environment that gave permission to people to talk about disability, share their lived experiences and ultimately to work towards a globally disability-smart organisation.

Recommendations

Purpose. A clear and compelling reason, or set of reasons, why Global Employee Disability Data collection is important, and what it is intended to achieve.

- Establish and agree a clear purpose(s) for data collection.
- Map the legal/quota requirements in your jurisdictions of operation – what is necessary?
- Map the legal restrictions in any other jurisdictions of operation – what is possible?
- Think beyond any necessary legal and compliance reasons, and consider the wider disability inclusion agenda – how can we use data to improve the working lives of people with disabilities?
- Consider the commercial purpose – what do your clients, stakeholders or shareholders think about disability inclusion?
- Be clear and consistent about the established purpose(s) in related communications and accompanying the data request itself.

Fundamentals. The globally consistent and locally resonant terminology, systems and resources, which makes Global Employee Disability Data collection work.

- Create a platform where employees can feel safe to self-I.D. and where they are confident their data will be secure. Where self-I.D. is not a legal requirement, disability data is being collected with the individual's consent and that consent must be freely given.
- Be clear about whether their self-I.D. will be identifiable or anonymised, and in either case, who has access to the data and how the data will be used.
- Create a globally acceptable and resonant self-I.D. question/statement/definition.
- Create country/context appropriate self-I.D. questions/statements, for more detailed information.

- Consider mapping local values to a global category system to enable consistent reporting across the globe.
- Utilise relevant data that may already exist, such as workplace adjustments data, rather than duplicating efforts. Multi-source data could be pulled together to create a disability inclusion scorecard (see page 38).
- Data, when collected, must be governed appropriately given it is bound by many different local legal and regulatory frameworks, so don't tackle this in isolation: work collaboratively with other departments and local D&I Leads / counterparts who have relevant expertise (Legal, Compliance, Data Privacy).
- Consider the learnings from self-I.D. of other diversity characteristics e.g. if your organisation has a high level of self-I.D. of sexual orientation, how did you get there? What were the lessons learnt?.

Leadership. Sponsorship, role modelling and accountability at the most senior level(s), which positions disability inclusion as a 'call to action' that impacts everyone.

- Appoint an executive sponsor for disability inclusion, who will be accountable for progress and lead the accountability of others.
- Communicate commitment to disability inclusion from the top of the organisation.
- Leverage the leadership platform to role model disability inclusion and to open the dialogue about disability for others.

Culture. An organisational culture of psychological safety and trust, which enables employees to talk openly about disability and lived experience, without fear of detriment.

- Set the scene about disability inclusion, before asking employees for self-I.D.
- Create FAQs that are easily available, to make information as transparent and consistent as possible.
- Be clear about the purpose for any data collection and what the benefits will be: for the organisation and for employees answer the "what's in it for me?"
- Work with ERGs to discuss the intended data collection; use their insights to create the best approach and request their support to enable people to participate.

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