Project Title
Working with terminal illness: what is known and what is needed
Summary
Many individuals diagnosed with a terminal illness still want / need to work and should be supported to until they no longer want to. However, several employer support documents often leave out mentioning it, despite its unique and challenging context. Furthermore, there is little information available about the number of working age people living with a terminal illness and the employment policies designed to support them. The initial research project had three stages; a scoping review of previous work in this area; a survey answered by over 1,000 HR professionals to give an insight into what support is currently offered; and a call of practice examples to provide case studies and obtain lived experience insights. They found "an employer lottery" with fewer than half of employers having policies. There were many pathways to impact including a successful launch event of the findings in the House of Lords and many well attended webinars. These webinars led to further collaborations such as with the LGA who created a terminal illness focused webpage for the organisations they support. We also hosted several workshops with large organisations to discuss their policies and current support. The project has had successful collaborations with people with lived experience, and relevant organisations like the TUC, FSB, LGA, SOM, ACAS, IES and CIPD. This collaboration resulted in the CIPD, who previously in their support guidance 'Long-term health conditions' only had a short paragraph around terminal illness, now creating a dedicated document based solely on supporting employees with a terminal illness. This guidance is due to be launched in early 2024 to all of their 150,000 HR members. The team also led a cohort of organisations (including a large TV Broadcaster, Universities, Biopharma company, large Highstreet brand, a fire & rescue department) in supporting them to write their own HR policies or managers guidance. These meetings enabled the cohort to help each other, speak to specialists and people with lived experience; many of these members are close to finalising their new procedures. The project also had a great impact at Marie Curie who have recently updated their policy following the research's recommendations and being a valid member of the cohort group. Marie Curie's HR team used the recommendations to reshape their policy, which will have an immense impact on the staff at the charity who have a terminal illness. Following the work with the cohort members, the team have launched guidance on workplace policies and practice to help more organisations develop their staff support. The guide was developed in collaboration with HR leads and occupational health professionals from across different workplaces. The guide has so far had success such as HR magazine recently writing about it and more organisations coming forward for further collaborations or positive stories about how they are using it. In summary, this project has had impact in both policy (updated public guidance) and practice (HR policies within organisations) as well as this it has opened doors for further conversations and further thinking in this area.
Who was the funder for this project?
Marie Curie

Are there any links or resources you want to share?
The research paper: https://whatworkswellbeing.org/wp-content/uploads/2022/11/WWW-Briefing-Dying-Well-2022.pdf Guidance for supporting people at work: https://whatworkswellbeing.org/resources/supporting-employees-with-terminal-illness/ Celeb endorsement of research: https://www.mariecurie.org.uk/media/press-releases/tv-presenter-jonnie-irwin-supports-calls-for-greater-employment-protection-for-dying-people/361087 LGA webpage: https://www.local.gov.uk/our-support/workforce-and-hr-support/wellbeing/managing-and-supporting-employees-terminal-illness HR magazine article: https://www.hrmagazine.co.uk/content/news/how-should-you-support-employees-with-a-terminal-illness