INDUSTRIAL INJURIES ADVISORY COUNCIL Minutes of the hybrid online RWG meeting Thursday 4 September 2025

Present

Dr Chris Stenton Chair Professor Gillian Leng IIAC Chair

Professor John Cherrie IIAC
Dr Jennifer Hoyle IIAC
Dr Ian Lawson IIAC
Mr Dan Shears IIAC
Professor Damien McElvenny IIAC

Ms Nicola Needham DWP IIDB Policy
Ms Roberta Owen DWP IIDB Policy

Dr Charmian Moeller-Olsen DWP IIDB Medical Policy

Ms Georgie Wood DWP IIDB Policy

Dr Marian Mihalcea Medical assessment observer

Mr Stuart Whitney IIAC Secretary
Mr Ian Chetland IIAC Secretariat
Ms Catherine Hegarty IIAC Secretariat

Apologies: Dr Richard Heron, Dr Matt Gouldstone, Dr Rachel Atkinson, Ms Lucy Darnton

1. Announcements and conflicts of interest statements

- 1.1. The chair set out expectations for the meeting and how it should be conducted. Members attending remotely were asked to remain on mute and to use the in-meeting options to raise a point.
- 1.2. Members were reminded to declare any potential conflicts of interest.
- 1.3. The public meeting date and venue is now live on the IIAC website. Members are asked to publicise this through their networks, the secretariat will share the link and the agenda.
- 1.4. The women's health scoping review was sent up for publication but was returned for issues to be resolved around accessibility. IOM reported that the issues have been resolved, and the report should be returned for publication in the very near future.

2. Minutes of the last meeting

- 2.1. The minutes of the meeting held in May 2025 were cleared with minor edits required for publication.
- 2.2. The action points were discussed and were cleared.

3. Neurodegenerative diseases (NDD) in sportspeople

Motor neurone disease (MND) draft paper

- 3.1. The chair summarised the progress of this investigation:
 - A full paper was presented at the last meeting where it was decided to cut this down to an information note.
 - The information note was drafted and discussed at full Council where it was agreed and signed off subject to minor changes.
 - A final version has been agreed and will be shared with the secretariat to be published.

Procurement exercise to review Parkinson's disease and cognitive impairment (dementia)

- 3.2. The chair updated members on the current status of the programme with Manchester University (MU) to review Parkinson's disease and cognitive impairment.
 - Several meetings have been held with MU and detailed protocols for both topics were provided and discussed at the last meeting.
 - The paper reviews are under way.
 - The project is progressing satisfactorily.
- 3.3. It was indicated that MU were waiting for formal acceptance of the protocols and that once received they will be published the secretariat indicated this would be done.
- 3.4. MU had been in touch to arrange a meeting in October to share a progress update. It was agreed that this didn't need to involve all members, but an update would be given at the next RWG meeting.
- 3.5. The point was made that MU will assess the quality of the studies it unearths, and this may also help with the studies identified for the MND investigation.

4. COVID-19

- 4.1. The chair introduced the topic by referring to the letter from the Minister for Social Security and Disability (MfSSD), Rt Hon Sir Stephen Timms MP, which set out a number of points of concern for consideration by the Council in relation to the COVID-19 command papers.
- 4.2. It was suggested by the MfSSD that postural orthostatic tachycardia syndrome (POTS) should be added to the 5 serious post-viral sequelae recommended for prescription in the published command papers. Because of that POTS was looked at again by a number of members and a paper circulated. It was felt that the other queries raised by the Minster could be dealt with by further explanation.

- 4.3. A member talked to the paper. The underlying problem in POTS is predominantly a failure of the autonomic nerve system control of reflexes that normally compensate for the effects of standing from sitting. This is possibly an effect of antibodies targeting autonomic nerves. In diagnostic terms, POTS is a relatively new condition, having been identified in the 1990s. It wasn't particularly well known before the pandemic and there are no quantifiable data relating to the effect of the pandemic on medical recognition of the syndrome. The extent of any biases is difficult to assess.
- 4.4. It was indicated that many papers on POTS have been published, and that not all are of good quality.
- 4.5. The tilt test which is used to diagnose POTS was described. This test evaluates how the body responds to changes in position. The subject lies on a table that gradually tilts to a near-standing position while monitoring heart rate and blood pressure. POTS is characterised by a rise in heart rate without an accompanying fall in blood pressure.
- 4.6. A member noted that only a small proportion of those with symptoms of POTS have the condition when tested objectively.
- 4.7. It was suggested that many published papers may not have undertaken objective testing, and this might have influenced the perceived prevalence of POTS.
- 4.8. It was noted that POTS has been associated with a number of other medical conditions including viral infections and is not unique to COVID-19.
- 4.9. The role of deconditioning was discussed and whether or not this is a cause of POTS or is secondary to it. Deconditioning occurs quite quickly on bed rest and is associated with abnormalities similar to those of POTS. After COVID-19, post-exertional malaise interfered with the ability of many to exercise. A number of papers indicate that exercise can improve POTS.
- 4.10. There is relatively little information about the natural history of POTS. By definition, the symptoms have to be present for at least 3 months. Some papers indicate that over 90% of people recover with exercise and it's not clear why those other patients don't recover.
- 4.11. There was discussion about the disability associated with POTS. Some members questioned the extent of disability given the normally relatively short-lived tachycardia on standing. Another member responded that there is a theory that POTS is a marker for a generalised disorder of autonomic nerve function. There are strong associations between POTS and 'brain fog', fatigue, irritable bowel syndrome etc. These conditions could be considered to be the disabling element(s) associated with POTS rather than simply the

- symptoms directly associated with the tachycardia. Another member drew attention to secondary effects or associations such as with anxiety.
- 4.12. A member noted that when claims for other (already prescribed) diseases are assessed, other associated factors are taken into consideration in assessing the level of disablement.
- 4.13. There was also discussion about the associations with COVID-19. A member asked if there is sufficient evidence to include POTS in the COVID-19 recommendations. Another member responded by stating that POTS can be caused by viral infections (such as COVID-19) however, it's not clear if the risks are doubled and the issue of deconditioning which might be associated with a premorbid condition might cloud the picture. A member quoted from the command paper which introduced the 5 serious pathological conditions for prescription their view was that POTS is not comparable to those conditions and as it is associated with a number of other causes the relationship with COVID-19 is unclear.
- 4.14. Members debated whether POTS should be included in the prescription with mixed conclusions. Some members were in favour and others indicating there would need to be caveats which could make it complicated for the assessors.
- 4.15. A member commented that whilst IIAC could suggest the wording for a prescription, the regulations have to be drafted for it to become law, so the wording might change. There might also be complications when writing the guidance/handbooks for decision-makers and medical assessors if the prescribed entity is complex.
- 4.16. A member commented that POTS may be difficult to include in the prescription as a number of other causes prior to having COVID-19 would need to be excluded before it could be considered to be linked to COVID-19, including other viral infections. Another member commented that they felt POTS would be difficult to incorporate into Industrial Injuries Disablement Benefit because of the points raised.
- 4.17. It was felt that for most people diagnosed with POTS, the corresponding disability would likely to be small. There was a suggestion that POTS could be an indirect indicator of long-COVID. A member felt that POTS was a physiological condition rather than pathological and the uncertainties are tangible.
- 4.18. A members felt that POTS may not be a clearly defined entity and may not be associated with persistent impairment. The issue of testing for POTS and who would be responsible for carrying this out was also discussed.

- 4.19. It was suggested that POTS could be included in the disability assessment when it accompanies any of the other 5 sequelae recommended for prescription.
- 4.20. There was also some discussion around the original command papers and whether the papers should be revisited especially related to the time-lines of doubled risks. It was noted that there have been marked changes to diagnostic testing for SARS-CoV-2 since the time the Command Papers were drafted.
- 4.21. The discussion concluded that RWG would recommend to full Council to not make any changes to the recommendations for prescription and to look again at the literature around the doubling of risk with objective tests.
- 4.22. It was agreed that the discussion would be summarised for the main Council.

5. The potential to use Real World Data' in IIAC's work

- 5.1. The chair introduced the topic and referred to the <u>NICE real-world evidence framework</u>.
- 5.2. A member took the lead indicating there is a train of thought around research and real-world data and how this can play into IIAC's work.
- 5.3. The NICE framework was discussed and how the organisation looked at sources of data other than controlled clinical trials, and how this data might be useful.
 - Real-world data is defined in the framework as... "Data collected outside the context of a controlled clinical trial, routinely collected data and be collected prospectively and may be used to address a specific research question"
 - Those datasets may be relevant for IIAC in relation to areas which could be looked at, possibly leading to recommendations for prescription, flagging up new things to examine i.e. new topics to address.
 - Other organisations, such as <u>NICE</u> (National Institute for Health and Care Excellence), looked at how real-world evidence was used in decision-making, rather than formal research studies.
 - There are data everywhere and the world has changed since IIAC was established – should IIAC embrace these new sources of evidence to use in its work?
- 5.4. The NICE framework was established over a number of years, with input from key stakeholders, workshops etc and has now been widely accepted.
- 5.5. A member suggested that should IIAC decide to pursue other sources of data, this would likely to be an iterative process over a period of time:
 - How could this be implemented?
 - How robust are the data?
 - When is it appropriate to use real-world data?
 - Could it be used to fill gaps in evidence?

- 5.6. A member thought the Council was moving in the direction of alternate sources of data during the COVID-19 investigations with the concept of the 'totality of the evidence' being introduced.
- 5.7. Another member felt that the Council was constrained by having to establish a more than doubling of risk to link occupation to a disease, but it was pointed out that this is merely a tool and the legislation states that 'reasonably certain' is quoted and how IIAC arrives at that conclusion is at its own behest.
- 5.8. A member commented that a constraint to the real-world data approach might be that occupation is rarely or poorly categorised in much of the routinely collected data, e.g. GP or hospital records.
- 5.9. It was pointed out that IIAC had used RIDDOR (Reporting of Injuries, Diseases and Dangerous Occurrences Regulations) data in the past and that this had been useful.
- 5.10. There was some further debate around the application of real-world data, including how datasets could be scrutinised and conclusions drawn out.
- 5.11. Summing up, the Chair stated it was likely that IIAC would be happy to use real-world data in addressing certain questions. Screening these data to source new topics to investigate would likely require resource and would require prioritisation against other potential area of investigation.
- 5.12. It was suggested that real-world data be discussed with the main Council to establish if alternative datasets would be useful in progressing IIAC's work. Having a catalogue of the datasets might also be useful if there are questions which the Council can't answer by conventional means, or the information could be used alongside traditional data as a comparator.
- 5.13. A member commented that the data from civil court cases for negligence would be useful but may be difficult to access. Other potential sources of information were briefly discussed.
- 5.14. Referring to the NICE framework, a member asked if the Council should have a standard template for the way information is to be extracted. It was felt that this would be useful for future investigations.
- 5.15. The IIAC Chair indicated that a process and methods document was being drafted, describing how IIAC works, and it was envisaged that this could contain templates in appendices, which would show how IIAC would want data to be structured and presented.
- 5.16. A comment was made that IIAC is dealing with more complex issues and likely to commission more external work, so it would be helpful to have a consistent structure around that.
- 5.17. It was agreed that a member would look at drawing up some suggestions around this.

6. Reviewing approach to revising existing prescriptions

- 6.1. The Chair referred to documents which had been circulated in meeting papers.
- 6.2. Reference was made to NICE processes and the difference between update and refresh, where the fundamentals of a prescription are not changed (e.g. where medical terminology has changed). Changing a prescription would likely require an evidence review whereas a refresh would not.
- 6.3. A member commented that there were a number of prescriptions which would benefit from review and another commented they felt the entire portfolio could be reviewed. Reference was made to the last time this was done by the Council, culminating in the '<u>Completion of the review of the scheduled list of prescribed diseases: IIAC report</u>' in 2007.
- 6.4. A list of suggested changes to prescriptions that had been drawn up following previous meeting was discussed. It was noted that there was no commonality between the diseases, and any changes would not be likely to result in an increase in claims. The intention would be 'tidy up' the prescriptions e.g. to remove some of the apparent restrictions and descriptors that are no longer relevant in the UK.
- 6.5. There was discussion around the relative benefits of carrying out a 'light-touch' review or carrying out a comprehensive review of all the prescriptions. It was suggested that as the prescriptions are legal entities, it might be wise to step back and give more consideration to what might be required and to perhaps look across the board, establishing if it needs to be high level or more detailed.
- 6.6. A member asked about the process of making changes to prescription and it was confirmed that if the wording of a prescription is changed, then the legislation would have to be changed IIAC's recommendations would need to be specified in command papers. It was pointed out that a number of small changes to prescription could be included in a single command paper.
- 6.7. If carrying out a review of selected prescriptions only a member asked if prescriptions with the most claimants should be selected or if prescriptions with fewer claimants that have restrictive occupational requirements should be selected. If the latter, this could open up eligibility to more workers who would be currently excluded.
- 6.8. A member suggested that a starting point for the respiratory disease prescriptions would be to look at those which have the occupational exposure as part of the disease definition, such as PD D1 or D3.
- 6.9. There was discussion around prioritisation and how 'quick win' prescriptions could be selected, possibly on the potential numbers of claimants impacted. It was also suggested that DWP IIDB policy may also have ideas on prescriptions to revise, so consultation/collaboration would be required.
- 6.10. Several members agreed that having lists of specific qualifying occupations was restrictive as lists can become outdated and are rarely revised. Several examples were discussed.

- 6.11. A member welcomed making the prescriptions more streamlined. There was some discussion around avoiding over-simplification and having too restrictive qualifying conditions in certain prescriptions. Over-simplifying a prescription might result in a jump in the number of applications for IIDB with not necessarily an increase in successful claims potentially overloading the claims process.
- 6.12. It was decided that a systematic review of all the prescriptions would be preferrable to a more restricted review. It was suggested that a high-level review be conducted and to use this to prioritise the way forward. There was some discussion on how this could be resourced. A final decision would lie with the main Council.
- 6.13. A number of specific issues were covered in discussion:
- 6.14. It was suggested (tentatively) that infection could be classified as an accident, so it is possible that some of the 'B' prescriptions could be reframed under the accident provision of IIDB, especially where there were very low (or zero) numbers of claims.
- 6.15. There was discussion around prescriptions which involve asbestos and how future exposures could be dealt with, given that buildings could be a source. It was pointed out that background asbestos levels are now significantly lower than when the prescriptions were written.
- 6.16. It was noted that the terminology 'diffuse' is now rarely used in relation to mesothelioma, but it was felt that removing it from the prescription might exclude some claimants.
- 6.17. A member asked about 'argument by analogy' relating to the prescription for mesothelioma where there may not be any direct epidemiological evidence to suggest that asbestos fibres can reach parts of the body not covered by the prescription. It was noted that mesotheliomas outside the pleura and peritoneum are rare, and it was felt that any change to the prescription could be formulated in such a way that claimants would not be disadvantaged.
- 6.18. It was noted that care is often needed in relation to terminology e.g., the use of 'respirable crystalline silica' rather than 'silica' as non-crystalline silica poses a much lower risk.
- 6.19. A member suggested that 'occupational exposure' would probably need to be defined. However, it was noted that the term 'substantial' appears in a number of prescriptions without any specifications of what that means.
- 6.20. A member suggested that the issue of potential doubling of risk of lung cancer in chromate production (identified in the Institute of Occupational Medicine report) could also be influenced by the numbers of workers exposed in cement production. This was considered to require a major review if taken forward.
- 6.21. A member raised the issue of occupational deafness and referred to the 'Noise, occupational deafness and Industrial Injuries Disablement Benefit: IIAC position paper 38' paper published in 2017. This paper reviewed the diagnosis question and

occupation element and to some extent, the associated disability. This member had concerns that the threshold for disability for hearing loss amounting to at least 50dB in each ear, being the average of hearing losses at 1, 2 and 3 kHz frequencies, is too high. This member made a plea for this prescription to be revised and offered to draft a paper setting out the issues as they felt the prescription is unfair and no new occupations had been added to the qualifying criteria.

7. AOB

- 7.1. The IIAC Chair raised the suggestion that a list of key stakeholders be drawn up which could be useful in future engagement.
- 7.2. It was agreed that the agenda for the forthcoming public meeting be circulated.
- 7.3. The Chair made members aware that if a disease is prescribed, it rules out claims under the accident provision.

Dates of next meetings

IIAC Meeting: 15 October 2025 (pm)

RWG Meeting: 27 November 2025