# INDUSTRIAL INJURIES ADVISORY COUNCIL

# Minutes of the hybrid online meeting Thursday 10 April 2025

#### Present:

Professor Gillian Leng IIAC Chair Dr Lesley Rushton Former Chair

Dr Chris Stenton IIAC Dr Ian Lawson IIAC Dr Richard Heron IIAC Professor John Cherrie **IIAC** Professor Max Henderson IIAC Professor Damien McElvenny **IIAC** Dr Jennifer Hoyle **IIAC IIAC** Dr Gareth Walters Dr Sally Hemming **IIAC** Ms Lesley Francois IIAC Dr Sharon Stevelink IIAC Mr Daniel Shears **IIAC** Mr Stephen Mitchell IIAC

Ms Lucy Darnton
Dr Clare Leris
Mr Lee Pendleton
Ellis Humphreys
Joy Atigogo
HSE observer
IIDB observer
IIDB observer
IIDB observer

Dr Rachel Atkinson Medical assessment observer
Dr Marian Mihalcea Medical assessment observer
Dr Sasa Markovic Medical assessment observer
Mr Andrew Hay Northern Ireland Department for

Communities (NI DfC)

Ms Patricia Quinn NI DfC

Dr Matt Gouldstone DWP IIDB medical policy

Ms Parisa Rezai-Tabrizi DWP IIDB policy
Ms Georgie Wood DWP IIDB policy

Dr Hilary Cowie Institute of Occupational Medicine

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

Apologies: None

### 1. Announcements, conflicts of interest statements and sign-off of minutes

- 1.1. The new Chair introduced herself and invited members to do the same. She noted that she had agreed that the former chair would chair the meeting for the items on neurodegenerative disease and women's health.
- 1.2. Members were asked to declare any conflicts of interest now or when an agenda item was due to be covered.
- 1.3. Bids had been invited to assist the Council with its work on neurodegenerative diseases in professional sportspeople. It was suggested that Prof Damien McElvenny may be asked to step away from the meeting when this item was

to be discussed due to being part of the University of Manchester bid team, but it was stated that no commercial or sensitive discussions would take place, so it was not felt necessary. Dr Stevelink declared that she was a deputy director for the London Centre for Work and Health but had distanced herself from being involved in any bids to carry out work for the Council.

1.4. Members and observers online were asked to remain on mute and to use the in-meeting options to raise a point.

#### 2. Minutes of the last meeting

2.1. The minutes of the January 2025 meeting and the action points had been circulated to members to comment on and agree. Action points were cleared or carried forward. The minutes were cleared with minor amendments.

### 3. Decision making - which diseases should be prescribed for IIDB

- 3.1. Members were reminded that there are 2 documents published on the IIAC gov.uk website, which are a compromise between a lay-person's and slightly technical approaches to the Council's work. The document which sets out the Council's decision-making process was outdated, as it focussed on point-estimates of risk, so work was undertaken to bring this up to date by considering uncertainty and acknowledging this.
- 3.2. The redrafted guidance had been circulated to members and comments were invited. Members were invited to comment further on the guidance at the meeting.
- 3.3. The Chair commented that she felt that the document was aimed at stakeholders and IIAC members to ensure IIAC is consistent in its approach (i.e.to hold IIAC to account). A member commented that the guidance is also intended to try to explain the complexities of the concepts IIAC has to work with when making judgements on topics.
- 3.4. The Chair also felt that perhaps more detail could be given on the link between occupation and disease where employment equals exposure to something. Plausibility around this could be brought out more, exploring the mechanisms involved. The point was made that IIAC doesn't have an expert on toxicology but has consulted on this when required. This gap could be something to consider for the next round of member recruitment.
- 3.5. A member commented that they felt that exposure equivalence could be covered as this approach has been used when considering evidence where epidemiology is missing or weak.
- 3.6. A member commented they felt that the draft guidance struck a good balance between being too technical and not technical enough a lay-person should be able to follow the rationales explained.
- 3.7. There was some discussion around bias, but it was felt the draft guidance covered this adequately.
- 3.8. A member raised a point around how much evidence is required and its quality; it was decided to consider expanding this concept in the draft guidance.

- 3.9. A member felt that the guidance would benefit from a summary as this is what most people would look for.
- 3.10. A member commented that if the decision-making guidance was too rigid or too prescriptive, this could be mis-used by stakeholders. They felt that each investigation is evaluated on merit and relies on the expertise present on the Council to assess the evidence. This is much more nuanced than relying on an algorithm. They felt the draft guidance struck the right balance.
- 3.11. Discussion followed on diversity of Council members and the perceived potential for bias and it was noted that the meeting minutes were detailed enough to demonstrate that members fully debate topics, members share their views and that differences of opinions are aired and noted.
- 3.12. A member considered that IIAC needs to be clearer on what it means when it refers to 'robust evidence" however, it was felt that this could be covered in individual reports which use this term as it may depend upon the evidence presented.
- 3.13. It was pointed out that the burden of proof to accept that there is a link between occupation/exposure to disease is based on the 'balance of probabilities'. This member commented that, on occasions, IIAC is looking for absolute proof which strays into the realms of 'beyond reasonable doubt' which is not the test. The legislation specifies what is required in terms of proof (presumed with reasonable certainty) which is also linked to the court's requirements for proof.
- 3.14. It was agreed that, following discussions, the document would be amended and recirculated. The Chair noted that decision-making on the Council aims for a consensus amongst members and that the test is on the balance of probabilities.

#### 4. Neurodegenerative diseases (NDD) in professional sportspeople

- 4.1. It was noted that there were 3 items for discussion on this topic:
  - The draft amyotrophic lateral sclerosis (ALS) paper
  - Update on the procurement exercise to review Parkinson's disease and cognitive impairment
  - Correspondence

#### The draft ALS paper

- 4.2. The former Chair opened the discussion by thanking members who have been investigating the link between ALS and professional sportspeople. They felt this has been a challenging topic to tackle and reiterated that some members have concerns about the amount of data identified and its quality. The Research Working Group (RWG) Chair was invited to take members through the draft paper for subsequent debate.
- 4.3. The paper circulated in meeting papers was a revised version following RWG discussions. The first point to note was nomenclature and now the paper refers to motor neurone disease (MND) as this more closely reflects an umbrella term which incorporates ALS ALS is more the commonly used American term.

- 4.4. The RWG Chair reported that the RWG felt that the paper should be reviewed again by an expert neurologist once a decision had been made by Council. They also relayed the discussions around the reliabilities of standardised mortality ratio (SMR) in that population rates for MND vary considerably geographically and it is difficult to arrive at a standardised population to make a reference population, particularly at younger ages. Discussions had also taken place around proportional mortality rates which some studies had presented, which could be artifactually elevated when a disease is rare and has low mortality rates.
- 4.5. The RWG Chair went on to mention the reliability of the data and diagnosis and gave an example of a study where 40% of the diagnoses of ALS on the population register were incorrect.
- 4.6. The issue of potential bias was then introduced where the mapping onto the population health index which showed that ~20-40% of footballers couldn't be mapped onto the health index whereas the entire reference population came from the health index. Another potential for bias was the recruitment of subjects from internet sites, social media or press reports. In 1 study, it was felt that ~25% of subjects recruited in this way didn't have ALS.
- 4.7. The RWG Chair also identified that the study on rugby players may have been carried out before the game became professional, so this may need to be addressed.
- 4.8. At the last RWG, there was no unanimity of opinions, but overall, the evidence suggested some increased risk, but whether or not this is doubled and unlikely to be overturned by subsequent studies is unclear.
- 4.9. The version of the paper circulated to members does not have a table summarising the evidence from the studies as RWG felt this may be misleading as giving more weight to the evidence, which was misleading due to overlapping studies using the same subjects.
- 4.10. The RWG Chair felt there was no more evidence to include at this time and opened up the discussion to members.
- 4.11. A member raised concerns that for the Scottish study on rugby players, no ALS cases were identified in the population control group and the methodology around dealing with this issue appeared to be flawed, elevating the risks. They felt this paper should not be included in the evidence for decision-making.
- 4.12. Summarising the totality of the evidence, a member felt there was very little if the rugby study was ignored, in reality around 4 studies on American football and soccer. Another concern was expressed about another Scottish study where all the different NDDs presented had the same risk estimates. An expert neurologist suggested that the mechanisms for each of the NDDs were different so could not be explained by having the same pathology. It was suggested that there may have been an under-estimation of the number of cases in the control populations. However, it was difficult to work out from the study methodology.
- 4.13. Commenting on the draft ALS paper, a member mentioned that whilst other members may have concerns about the studies, the paper doesn't pick apart

- the studies in sufficient detail to justify the concerns. If this can't be done, then the Council has to accept the evidence as it is published. This member also commented that the discussions around bias should focus on that which could inflate the risk estimates.
- 4.14. The Chair commented that it is difficult to understand mechanisms when the aetiology of MND isn't clear where genetic factors, aggregates of transactive response-binding proteins and geographical variations all have an impact. This indicates there is a lot of uncertainty and any studies would need to be really well matched. They felt that IIAC could make recommendations or suggestions for studies to be carried out, which may have been done many years ago where IIAC hadn't identified suitable studies to confirm links with occupation and disease. It was noted that IIAC often identifies gaps in evidence, but making recommendations on how studies should be carried out is not something which IIAC has done. This could be considered.
- 4.15. A member commented that they were leading a study looking at mortality of former footballers in England funded by the Colt Foundation and whilst they did not suggest waiting for this study to be published, it may have the potential to add to the evidence base for IIAC's investigation.
- 4.16. Returning to the suggestion that IIAC could make recommendations on how studies should be carried out, a member felt that highlighting the gaps in published studies should be sufficient as having strong links to bodies who do the studies could compromise its independence. There was some further discussion around this topic where it was felt that in some instances, this may be an appropriate approach to take.
- 4.17. A member commented that the Council was being over cautious when evaluating the evidence and felt that prescription should be recommended. They felt that if the Council were to wait for any new evidence, this could leave it 'behind the curve' especially when some employers were taking steps to limit potential steps to regulate exposures. They felt that elements within the report which gave a plausible account of how prescription could be achieved.
- 4.18. The topic of presumption was introduced and there was some discussion around this and the requirement of the legislation to have proof of a link between disease/exposure and work, presumed with reasonable certainty. Some examples were given such as COPD or osteoarthritis of the knee, which are not exclusively occupational diseases. The point was made that perhaps having all the evidence available should not be a bar to making recommendations for prescriptions.
- 4.19. A member thought the evidence required by industry to make recommendations are generally lower than the bar which is required for industrial injuries disablement benefit.
- 4.20. The point was made that the Council published a position paper 'Diseases with multiple known causes and rebuttal' which indicates that a disease can have occupational and non-occupational causes and if both can have a factor more than 50%, then both can be included. It was also noted that the Council had published an earlier report 'Industrial diseases: presumption that a

- <u>disease is due to the nature of employment: IIAC report'</u> which it was felt would be useful for members to familiarise themselves with.
- 4.21. The mechanism of potentially linking ALS to professional sportspeople was revisited where a member felt that this this didn't follow logically in the draft ALS paper. It was commented this was a complex area which was difficult to cover as there is a potential for reverse-causality. There is not a clear mechanistic pathway which can explain the exposure leading to disease.
- 4.22. A member asked if the Council could be confident in making recommendation for prescription when 3 different sports were being compared.
- 4.23. A member felt that they were not convinced that the evidence for soccer showed a doubled risk and if that risk was doubled, could this be subsequently overturned by future studies. This was countered by stating that it would require a number of different future studies to overturn the evidence, which they felt was sufficient to make recommendations for prescription even though there were faults with the studies from where this was drawn.
- 4.24. There was some discussion around potential markers for exposure relating to playing position, but this evidence was considered very weak.
- 4.25. A member felt that looking at the evidence as a whole and quoted from the draft paper "The evidence should ideally come from several independent studies and be sufficiently robust that further research at a later date would be unlikely to overturn any conclusions" that in this instance prescription was not appropriate. Several members agreed and it was felt that the section could be expanded with more details on why there was disquiet amongst members about the quality of some of the evidence.
- 4.26. A member felt that focussing on why members felt there were methodological flaws in some of the studies would read easier and be a more persuasive argument. This was supported by a number of members who also felt that the complexity of the investigation could be brought out more in the draft paper.
- 4.27. A member had a different opinion and stated that the Council could prescribe as they felt the evidence was sufficient, giving the following reasons after reading the draft paper:
  - Some of the evidence from head injury suggests there may be an increased risk of MND
  - Early onset amongst sportspeople occurs and increases the biological plausibility of the association
  - There are 3 recent systematic reviews which say there is an association between either sports or intense physical exercise and MND.
- 4.28. This member felt that if the Council is not minded to recommend prescription then the report needs to explain very clearly why the points mentioned are not important.
- 4.29. It was noted that there was no decision at this point, with members were asked to consider the points raised and to submit their views to help the Council make a decision. It was noted that the topic is sensitive and has attracted a lot of stakeholder attention. The members who had put a considerable amount of work into this draft paper were thanked for their efforts.

# Update on the procurement exercise to review Parkinson's disease and cognitive impairment.

- 4.30. The secretariat gave a brief update on the procurement exercise:
  - 4 organisations were provided with bid packs following the expression of interest posted on the IIAC website.
  - 3 organisations stated they wished to bid for both lots.
  - The closing date to return the bid packs was 29 April
  - Bids will be evaluated starting 30 April
  - Preferred bidders to be appointed w/c 12 May
  - Unsuccessful bidders will receive feedback.

#### Correspondence

- 4.31. A firm of solicitors wrote to the Council requesting copies of the written information provided by Professor Talbot when an earlier version of the draft ALS paper was reviewed. This was in relation to "Multiple Claimants v Various Rugby Unions".
- 4.32. The secretariat explained the options available to the Council and it was noted that Professor Talbot would need to be consulted prior to releasing anything.
- 4.33. Further advice was deemed to be required.

#### 5. Scoping review into women's occupational health

- 5.1. Members were reminded that the Institute of Occupational Medicine (IOM) was commissioned by the Council to carry out a scoping review into women's occupational health, which had recently concluded. A draft report from IOM had been circulated to members in meeting papers and Ms Cowie thanked members for their comments.
- 5.2. The Chair invited Ms Hilary Cowie to give an overview of the findings.
  - The research comprised a review of the epidemiology literature on work and non-malignant diseases relevant to women in workforce, in order to complete the following objectives:
    - (i) To search for authoritative reviews and (where absent for a topic) large-scale cohort or case-control studies to identify the industries, occupations and exposures associated with non-malignant occupational diseases that occur (a) only in women or (b) where women are at greater risk than men where both are similarly exposed.
    - (ii) To give an approximate estimate, where feasible, of the range of the magnitude of the risks and the numbers/proportions likely to be affected.
    - (iii) To assess the size of the literature base for outcomes/exposures for more detailed evaluation of specific health outcomes and occupations.

- (iv) To produce a final report and brief interim reports as appropriate.
- 5.3. The search strategy included looking at information on employment patterns in women and by looking at the 3 general reviews of gender and occupational health highlighted within the study proposal.
  - 14 occupations/occupational groups with over 100,000 women workers in the UK were identified.
  - These comprised: healthcare, admin/office roles, childcare, cleaning, animal care, hair and beauty, teaching, retail, pharmacy, social services/work, welfare, hospitality, science and fitness.
- 5.4. Ms Cowie gave an overview of the search strategies used and the considerations given to progress the investigation. The results were then considered.
- 5.5. Final screening resulted in 306 studies which were considered for inclusion.
- 5.6. Key findings by occupation were discussed and examples given:
  - Animal Care Workers
  - Carers
  - Childcare workers
  - Cleaners
  - Fitness workers
  - Hairdressers
  - Healthcare workers
  - Hospitality workers
  - Office workers
  - Scientists
  - Shiftwork
  - Social workers
  - Teachers
  - Other occupations
- 5.7. Health conditions within each occupation were discussed and examples included:
  - Musculoskeletal disorders
  - Mental health (e.g. stress/depression/suicide)
  - Respiratory diseases
  - Reproductive health
  - Violence/assault
  - Other health outcomes (e.g. urinary incontinence, lower urinary tract symptoms, skin disorders)
- 5.8. More details were given for each occupation/health conditions and there was discussion around the implications of these.
- 5.9. The Chair commented that this was a very comprehensive and detailed review and thanked Ms Cowie/IOM for the quality of the work.
- 5.10. Members were encouraged to read the IOM report again in light of the presentation delivered and provide any further feedback to Ms Cowie.
- 5.11. The Chair commented that the outcomes of the scoping review presented opportunities for the Council to take forward in its work programme. She

asked about cardiovascular diseases as this didn't seem to feature in the report. Ms Cowie indicated that the principal health outcomes were selected from recent reviews. IOM also searched by occupation without limiting potential health impacts so cardiovascular diseases should have shown up. Ms Cowie agreed to check the more general papers which dealt with women's health.

- 5.12.A member commented that this was an impressive report and asked Ms Cowie what occupations/health outcomes suggested a doubling of risk. Ms Cowie suggested that of papers which gave relative risks or odds ratios, none appeared to be greater than 2, so generally speaking, none with high risks. Ms Cowie indicated that where there was robust evidence, this was highlighted in the report.
- 5.13. This led onto a discussion about whether IIDB best serves the needs to women and whether IIAC's decision-making could account for this.

# 6. Commissioned review on respiratory diseases (RD)

- 6.1. The IOM reports had been finalised and the summary report drafted.
- 6.2. The summary report was circulated in meeting papers along with a suggested introductory paragraph for the website to aid when the reports are published.
- 6.3. IOM indicated that when the reports are published, the links will be placed on IOM's website.
- 6.4. The introductory paragraph was approved by members.

#### 7. IIAC public meeting 2025

- 7.1. The Chair felt that IIAC's public meetings were an important instrument for stakeholder engagement. However, due to the changeover between Chairs, it was suggested that the public meeting be held in October rather than July and be held in London.
- 7.2. It was also suggested that the IIAC meeting and the public meeting be held on the same day.
- 7.3. A member felt that having the opportunity to meet with their colleagues at the public meeting, which was supported by other members. Consequently, it was agreed to hold the meeting in October and to stick with the usual format of having the IIAC meeting in the afternoon before the public meeting, which would then be a full day.
- 7.4. London was agreed as the location.

#### 8. IIDB policy team update

- 8.1. It was indicated that advice on the IIAC COVID-19 papers had been sent up to ministers.
- 8.2. A member asked about the other command papers which had yet to be assessed by DWP a policy official stated that the other papers had yet to be impacted as the COVID-19 papers were prioritised.

## 9. **AOB**

9.1. An observer from the Ministry of Defence stated that the Independent Medical Expert Group which advises on the Armed Forces Compensation

Scheme has advertised for a new Chair. Although the role has traditionally been unpaid, if members were interested in applying but on a paid basis, then to please make contact with Dr Clare Leris to inform further discussions.

#### Head injury cases in professional rugby class action

- 9.2. A member with legal expertise indicated that the action had been brought against various rugby unions governing bodies. The claims were being made for a number of NDD such as early onset dementia, chronic traumatic encephalopathy (CTE), post-concussion syndrome, epilepsy, Parkinson's disease and MND.
- 9.3. The arguments given were that negligence on the part of the governing bodies to have not informed players of the risks and failure to protect players from the risks of injuries.
- 9.4. The latest hearing indicated that a pool to test cases would be selected. Further hearings would be heard in July and December. A possible trial date for 2026 had been suggested.
- 9.5. It was agreed to keep members updated.

#### Other business

- 9.6. The secretariat expressed their warm thanks to the former Chair and wished Dr Rushton well for the future.
- 9.7. Dr Rushton reciprocated and stated the last 7 years as Chair had been very rewarding and was very proud of the way the Council had functioned. DWP officials were also thanked.

#### Date of next meetings:

RWG – 29 May 2025 IIAC – 10 July 2025