CPG on cancer: Clinical Trials session

Key Details

When: 13:00-14:00pm, Thursday 14th of December 2023

Where: MS Teams

Purpose of the Session: To hear from clinical trials experts about the state of trials within Wales.

Topic

This session was focussed on clinical trials with presentations from Dr Ceri Bygrave, clinical lead in myeloma and Joe Kiely, Science policy advisor at Cancer Research UK.

Agenda

- Welcome from Chair (1:00-1:05pm)
- Presentation from Dr Ceri Bygrave (1:05-1:20pm)
- Q&A (1:20- 1:30)
- Presentation from Joe Kiely (1:30-1:45pm)
- Q&A (1:45 pm-1:55 pm)
- AOB (1:55-2:00pm)

Attendees

1. Megan Cole
2. Simon Scheeres
3. David Rees MS
4. Mark Isherwood MS
5. Ceri Bygrave
6. Joe Kiely
7. Hannah Wright
8. Hilary Webb
9. Hannah Buckingham
10. Dr Lee Campbell
11. Thomas Owen
12. Eirlys Edwards
13. Emily Hearne
14. Greg Pycroft
15. Alison Yandall
16. Tom Crosby
17. Louise Carrington
18. Mandy Edwards
19. Thomas Brayford
20. Dawn Casey
21. Tessa Marshall

22. Judi Rhys
23. Ceri Hogg
24. Lowri Griffiths
25. Jenni Macdougall
26. Nicholas Jones
27. Jacob Sinkins

Minutes

- David Rees introduces the meeting and the speakers, Dr Ceri Bygrave, consultant haemotologist and clinical lead at UHW Cardiff, Ceri will be speaking about her experience of the clinical trials environment in Wales.
- David then introduces Joe Kiely, Policy Adviser at Cancer Research UK, who will be outlining the recent Clinical trials workforce survey conducted by Cancer Research UK.
- David then invites Ceri to present first.

- Ceri begins by introducing herself and her role within the Welsh clinical landscape and outlines the topics which she will cover, including why do we need blood cancer trials in Wales and why are patients missing out on research in Wales.
- Ceri highlights that access to medicine is the biggest challenge in patients receiving the level of care they deserve, owing to the need for blood cancer trials due to the complex nature of blood cancers.
- Ceri then introduces blood cancers, highlighting that blood cancers are the 5th most common cancer in the UK, with the 3rd highest cancer deaths.
- Ceri highlights that the number of blood cancer diagnosis have dropped since the pandemic, and this is due to patients presenting later and being diagnosed later.
- Ceri goes on to outline what myeloma is, identifying that 16 people are diagnosed with the disease each day, and shows that 20% of patients will die less than 2 years after diagnosis. Ceri further highlights suspected survival, and suggests clinical trials often act as a life line for people with this lethal cancer.
- She then outlines the current and previous trials in the myeloma space, showing how trials have continued to improve myeloma survival.
- She also identifies how expensive it is to treat myeloma, with 40% of NHS England spend being taken up by myeloma drugs.
- The cost of treating someone with DRD is £400,000 per patient.
- Ceri identifies that clinical trials can often be cost saving, due to the expense of these drugs and how drugs for trials are provided for free.
- She then discusses how myeloma is deemed a cancer of unmet need.
- Ceri further discusses how patients' perspective influencing ways of working, highlighting that patients are keen to participate in trials however, a lack of trials in Wales and all trials being centred in Cardiff means some patients miss out.
- She discusses how higher levels of deprivation in Wales mean that survival is poorer in certain parts of Wales.
- Wales attracts less than half of its proportional participation funding and has worsened post pandemic.

- Ceri outlines how the cancer improvement plan has committed to health boards offering patients trials where possible. However, this is not happening currently.
- Ceri goes on to list the main blockers to clinical trials in Wales, discussing staff resources and workforce issues, contracting delays, facilities and equality, diversity and inclusion meaning those from groups with protected characteristics miss out.

- David then introduces the next speaker, Joe Kiely.

- Joe Kiely begins by introducing himself and says how his presentation will complement Ceri's particularly the focus on barriers to clinical trials.
- Joe begins by outlining the scope and goals of the workforce survey, and discusses the recent manifesto for cancer research and care as published by CRUK. Highlighting how many recommendations are England focussed by many also apply UK wide.
- Joe discusses how the survey was produced to highlight the experiences of clinicians themselves and platform the barriers that clinicians experience within the field.
- Joe provides and overview of the survey outlining the survey launching over the summer and how they received 637 responses, with 4% of respondents being based in Wales which is close a proportional representation based on census data.
- Joe discusses how the survey will continue to expand and hopefully receive more respondents from the Devolved Nations.
- Joe provides a summary of the overall trends from the survey. Discussing how 3/4 clinicians acknowledging how it has become harder to deliver clinical research in the past 18 months.
- The rest of the survey goes on to try identifying why clinicians feel this.
- With the top barriers being wider staff pressures in the NHS, staff vacancies, lack of dedicated time for research and a lack of accountability and prioritisation for research within the NHS.
- The survey also saw a link between all the above with many elements interlinking to contribute towards pressures.
- The survey also explored clinician's feelings and the impacts on career intentions. With 1/3 of respondents considering leaving the field within the next 5 years, and a further 50% of that group consider leaving the field within the next two years.
- The three main reasons identified for people leaving were bureaucracy setting up research, limited opportunities for career progress and contract security and pay.
- Joe then outlined the next steps for the survey, with the full report being launched in January and its raw data being made available for those interested.
- Joe also hopes that the survey will influence the development of the UK clinical research workforce plan.

- David then opens the call for questions.

- Ceri begins by praising Joe's presentation and further outlining her experiences in relation to Joe's points about clinician's experiences of trials.

- Tom Crosby then outlines his experiences from Velindre and discusses how service pressures often mean trials are sacrificed. Tom also discusses the lack of appetite for research within the Welsh health agenda.

- Dr Lee Campbell asks a question, about how workforce pressures have contributed to commercial trials growing, however this means that research may not be made available.

- Ceri answers Lee by discussing how a balance is needed between commercial and academic/NHS trials. With commercial trials helping patients access drugs not available through NICE. Ceri also discusses how recently UHW have been spending commercial trial money on staff to fix workforce issues.

- Joe further chimes in to say that the problem is not a lack of strategies or plans from government, as seen by the O'Shaughnessy review and how policy strategies may seem promising however, they are not translating into action.

- Mark Isherwood, highlights the work of the CPG on medical research and how a collaboration between the two CPG's would be promising for working together in Wales to improve the clinical landscape.

- David Rees then closes the meeting by thanking the speakers and attendees.

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