

Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Wednesday 23 May 2018

Venue: National Institute for Health and Care Excellence
Level 1A, City Tower
Piccadilly Plaza
Manchester
M1 4BT

Present	1. Dr Peter Jackson	Present for all notes
	2. Sotiris Antoniou	Present for all notes
	3. Dr Ayesha Ali	Present for all notes
	4. Sarah Davis	Present for all notes
	5. Stuart Davies	Present for all notes
	6. Carrie Gardner	Present for all notes
	7. Jeremy Manual	Present for all notes
	8. Francis Pang	Present for all notes
	9. Linn Phipps	Present for all notes
	10. Dr Glenda Sobey	Present for all notes
	11. Professor Lesley Stewart	Present for all notes

In attendance:

Helen Knight	Associate Director, National Institute for Health and Care Excellence	Present for all notes
Sheela Upadhyaya	Associate Director, National Institute for Health and Care Excellence	Present for all notes
Joanne Ekeledo	Project Manager, National Institute for Health and Care Excellence	Present for all notes
Thomas Paling	Technical Analyst, National Institute for Health and Care Excellence	Present for all notes
Ian Watson	Technical Adviser, National Institute for Health and Clinical Excellence	Present for all notes
Mandy Tonkinson	Administrator	Present for all notes

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Rob Riemsma	ERG Representative	Present for notes 1 to 12
Isaac Corro Ramos	ERG Representative	Present for notes 1 to 12
Prof Nick Shaw	Clinical Expert	Present for notes 1 to 12
Prof Zulf Mughal	Clinical Expert	Present for notes 1 to 12
Margarita Vidal	Patient Expert	Present for notes 1 to 12
David Smeaton	Patient Expert	Present for notes 1 to 12
Joanne Taylor	Patient Expert	Present for notes 1 to 12
Oliver Gardiner	Patient Expert	Present for notes 1 to 12
Edmund Jessop	Commissioning Expert	Present for notes 1 to 12

Non-public observers:

Helen Barnett	Editor, National Institute for Health and Clinical Excellence	Present for all notes
Dr Steve Edward	Head of HTA BMJ-TAG	Present for all notes
Heidi Livingstone	Senior Public Involvement Adviser, National Institute for Health and Clinical Excellence	Present for all notes

Notes

Welcome

1. The Chair welcomed all members of the Committee and other attendees present to the meeting. The Chair reviewed the agenda and timescales for the meeting, which included the evaluation of burosumab for treating X-linked hypophosphataemia.
2. Apologies were received from Prof Ron Akehurst, Dr Shehla Mohammed and Dr Mark Sheehan.

Any other Business

3. None

Evaluation of of burosumab for treating X-linked hypophosphataemia

Part 1 – Open session

4. The Chair welcomed the invited experts: Oliver Gardiner, Edmund Jessop, Prof Zulf Mughal, Prof Nick Shaw, Joanne Taylor and Margarita Vidal to the meeting and they introduced themselves to the Committee.
5. The Chair welcomed company representatives from Kyowa Kirin to the meeting.
6. The Chair asked all Committee members to declare any relevant interests
 - 6.1. Dr Ayesha Ali, Sotiris Antoniou, Paul Arundel, Sarah Davis, Stuart Davies, Carrie Gardner, Jeremy Manuel, Francis Pang, Linn Phipps, Dr Glenda Sobey, Professor Lesley Stewart all declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the Evaluation of burosumab for treating X-linked hypophosphataemia
7. The Chair asked all NICE Staff to declare any relevant interests.
 - 7.1. Helen Knight, Joanne Ekeledo, Thomas Paling, Ian Watson and Mandy Tonkinson declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of of burosumab for treating X-linked hypophosphataemia.
 - 7.2. Sheela Upadhyaya declared a personal non-specific interest as she has chaired the Rare MSK Priority setting partnership for which the XLH Network is a partner organisation.
 - 7.2.1. It was agreed that this declaration would not prevent Sheela Upadhyaya from participating in this section of the meeting.
8. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
 - 8.1. All declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of of burosumab for treating X-linked hypophosphataemia.
 - 8.2. Prof Nick Shaw declared a personal non-specific financial interest as he has been in receipt of sponsorship from the company.
 - 8.2.1. It was agreed that this declaration would not prevent Prof Nick Shaw from participating in this section of the meeting
 - 8.3. Prof Zulf Mughal declared a personal non-specific financial interest as he received honoraria from the company for speaking at educational meetings on XLH and is the UK lead for the XLH registry which is sponsored by the company.
 - 8.3.1. It was agreed that this declaration would not prevent Prof Zulf Mughal from participating in this section of the meeting.

- 8.4. Joanne Taylor declared a non-personal specific financial interest as Metabolic Support UK had received a grant from the company.
 - 8.4.1. It was agreed that this declaration would not prevent Joanne Taylor from participating in this section of the meeting.
9. The Chair introduced the lead team, Dr Glenda Sobey, Jeremy Manuel and Stuart Davies who gave presentations on the clinical effectiveness and cost effectiveness of burosumab for treating X-linked hypophosphataemia.
10. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
11. The Chair explained that “representatives of the press and other members of the public be excluded from the remainder of this meeting having regard to the confidential nature of the business to be transacted, publicity on which would be prejudicial to the public interest” (Section 1(2) Public Bodies (Admission to Meetings) Act 1960)” and all public attendees left the meeting.
12. The Chair then thanked the experts and company representatives for their attendance, participation and contribution to the evaluation and they left the meeting.

Part 2 – Closed session

13. Discussion on confidential information continued. This information was supplied by the company.
14. The Committee continued to discuss the clinical and cost effectiveness of burosumab for treating X-linked hypophosphataemia.
 - 14.1. The committee decision was based on consensus.
15. The Committee instructed the technical team to prepare the [Evaluation Consultation Document (ECD) or Final Evaluation Determination (FED)] in line with their decisions.

Date, time and venue of the next meeting

16. Thursday 28 June 2018 at National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT.