

Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Wednesday 25 July 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. Prof Ron Akehurst	Present for all notes
	3. Dr Ayesha Ali	Present for all notes
	4. Stuart Davies	Present for all notes
	5. Carrie Gardner	Present for all notes
	6. Jeremy Manual	Present for all notes
	7. Dr Shehla Mohammed	Present for all notes
	8. Linn Phipps	Present for all notes
	9. Dr Mark Sheehan	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
Mandy Tonkinson	Administrator National Institute for Health and Clinical Excellence	Present for all notes
Ian Watson	Technical Adviser, National Institute for Health and Clinical Excellence	Present for all notes

Thomas Paling	Technical Analyst, National Institute for Health and Care Excellence	Present for all notes
Nigel Armstrong	ERG Representative	Present for notes 5 to 13
Oliver Gardiner	Patient Expert	Present for notes 5 to 13
Edmund Jessop	Commissioning Expert	Present for notes 5 to 13
Prof Zulf Mughal	Clinical Expert	Present for notes 5 to 13
Rob Riemsma	ERG Representative	Present for notes 5 to 13
Joanne Taylor	Patient Expert	Present for notes 5 to 13
Margarita Vidal	Patient Expert	Present for notes 5 to 13

Non-public observers:

Helen Barnett	Editor, National Institute for Health and Care Excellence	Present for all notes
Anna Brett	Technical Analyst National Institute for Health and Care Excellence	Present for all notes
Jess Cronshaw	Technical Analyst National Institute for Health and Care Excellence	Present for notes
Karen Samuels	All Wales Therapeutics and Toxicology Centre	Present for all notes
Pratit Shah	Administrator, National Institute for Health and Care Excellence	Present for all notes
Lydia Shears	Public Involvement Adviser, National Institute for Health and Care Excellence	Present for notes 5 to 13
Amaka Umeweni	Technical Adviser, National Institute for Health and Care 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 evaluations of burosumab for treating X-linked hypophosphataemia.
2. The Chair informed the Committee of the non-public observers at this meeting: Helen Barnett, Anna Brett, Jess Cronshaw, Karen Samuels, Pratit Shah, Lydia Shears and Amaka Umeweni
3. Apologies were received from Sotiris Antoniou, Dr Paul Arundel, Sarah Davis and Francis Pang.

Any other Business

4. None.

Evaluation of burosumab for treating X-linked hypophosphataemia.

Part 1 – Open session

5. The Chair welcomed the invited experts: Nigel Armstrong, Oliver Gardiner, Edmund Jessop, Prof Zulf Mughal, Rob Riemsma, Joanne Taylor and Margarita Vidal to the meeting and they introduced themselves to the Committee.
6. The Chair welcomed company representatives from Kyowa Kirin to the meeting.
7. The Chair asked all Committee members to declare any relevant interests
 - 7.1. Dr Ayesha Ali, Stuart Davies, Carrie Gardner, Jeremy Manuel, Dr Shehla Mohammed, Linn Phipps, Dr Mark Sheehan, Dr Glenda Sobey, Professor Lesley Stewartall 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.
 - 7.2. Professor Ron Akehurst declared a non-personal specific financial interest as the company for which he is Chairman and shareholder is providing services to Kyowa Kirin in relation to another health technology assessment case, although he has not been directly involved.
 - 9.2.1 It was agreed that this declaration would not prevent Prof Ron Akehurst from participating in this section of the meeting.
 - 7.3. Dr Paul Arundel sent apologies for this evaluation due to his stakeholder involvement within the British Paediatric & Adolescent Bone Group.
8. The Chair asked all NICE Staff to declare any 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 burosumab for treating X-linked hypophosphataemia.

9. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
 - 9.1. Nigel Armstrong, Oliver Gardiner, Edmund Jessop, Rob Riemsma, Joanne Taylor and Margarita Vidal 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.
 - 9.2. Prof Zulf Mughal declared a personal non-specific financial interest he is the UK lead for the XLH registry and he has received honoraria from the company for speaking at educational meetings on XLH.
 - 9.2.1. It was agreed that this declaration would not prevent Prof Zulf Mughal from participating in this section of the meeting
10. The Chair introduced the key themes arising from the consultation responses to the Evaluation Consultation Document (ECD) received from consultees, commentators and through the NICE website.
11. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
12. 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.
13. 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

14. Discussion on confidential information continued. This information was supplied by the company.
15. The Committee continued to discuss the clinical and cost effectiveness of burosumab for treating X-linked hypophosphataemia
16. 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

17. Thursday 23 August 2018, 10am at National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT.