

Clinical Steering Group Meeting

Monday 7 March 2019, 11:00-13:00

Research Board Room, Royal College of Surgeons of England

UNCONFIRMED MEETING MINUTES

Present:

Kieran Horgan (Chair)
Karen Clements
David Cromwell
Marianne Dillon
David Dodwell
Deborah Felon
Catherine Foster

Ashu Gandhi
Melissa Gannon
Eluned Hughes
Yasmin Jauhari
Ian Kunkler
Jibby Medina

Andrew Murphy
Emma O'Sullivan^ (by TC*)
Emma Pennery
Tom Robinson (by TC*)
Nisha Sharma
Sophia Turner

Apologies:

Pat Fairbrother
Margot Gosney
Lis Grimsey
Chris Holcombe

Jacquie Jenkins^
Fiona MacNeill
Stanley Ralph
Janice Rose

Alistair Ring
Richard Simcock
Lynda Wyld

1. Welcome, Introductions and apologies

- The chair welcomed the group to the Clinical Steering Group (CSG) meeting for the National Audit of Breast Cancer in Older Patients (NABCOP). All members in attendance introduced themselves, and apologies were given for those unable to attend. Two members attended this meeting by Teleconference*.
- The chair welcomed Emma O'Sullivan, Deputy Director of Quality Assurance for the Screen Quality Assurance Service at Public Health England. Attending as deputy for Jackie Jenkins^.

2. Declaration of any conflict of interest

- None at this time

3. Minutes of the last Clinical Steering Group meeting on the 26 November 2018, and matters arising

- The 26th November 2018 meeting minutes were reviewed and accepted as a true and accurate record of the meeting.
- Regarding Action 26/11-01 (from the previous CSG): AM, KC and the project team have been in dialogue regarding the addition of a data item, recording whether patients receive a triple diagnostic assessment in a single visit, to COSD V9 data collection. It has now been confirmed that this will be available from April 2020. The chair took the opportunity to thank AM for his valuable contribution.

Action 07/03-01: The PT will update the CSG on progress working with NCRAS to specify items for NABCOP to be included in COSD V9.

4. Clinical Steering Group membership

- Janice Rose has taken on one of the roles as patient representative for Independent Cancer Patients' Voice within the NABCOP CSG. She was unable to attend the current meeting, but aims to attend the next meeting in November.

5. NABCOP 2019 Annual Report – 1st draft

Members of the project team talked through the chapters of the draft 2019 Annual Report (AR).

a) Methods and 'How to read and understand the report' document:

- The PT have produced a separate document on "How to read and understand the report", containing guidance on how to navigate the sections of the report, the source of the datasets and how these are manipulated, interpretation of figures of NHS organisational breakdowns and improving local data quality. The next draft of the AR will signpost to this document. IK suggested that this document could be added as an appendix to the AR, and suggested a title of "Explanatory notes on the Methodology of the 2019 Annual Report".

Action 07/03-02: The PT will consider the feedback provided by the CSG on the 'How to read and understand the report' document, and continue to explore how it can best support the 2019 AR.

Action 07/03-03: The PT will circulate a copy of the 'How to read and understand the report' document with the minutes of this meeting. The PT would be grateful for feedback from the CSG on this document.

b) Patient Cohort and data completeness:

- The NABCOP 2019 AR will report on data linked from the 2015 Cancer Patient Experience Survey (CPES) to NABCOP patient-level data. This is the first time this has been done. The patients reporting CPES data are also included in the main patient cohort.
- The CSG discussed Trust exclusion. IK highlighted that it may be worthwhile to state how many Trusts are diagnosing fewer than 30 patients a year, and to further explore why these Trusts are treating such few patients. KC offered for NCRAS to explore this. YJ stated that all excluded Trusts are detailed at the end of the report.
- The PT listed the additions to data completeness for the report and presented table 3.1. IK suggested using a traffic light system for highlighting Trust data completeness in the report.
- The PT have worked with KC to collect accounts of Trusts achieving good data completeness to be disseminated, in the form of case studies alongside the AR. The CSG were asked to provide feedback on this and recommend Trusts that could be cited as further case studies. IK felt that examples of good practice should be included clearly, at the front of the report, rather than in a separate document. NS further suggested that contact details for the featured Trusts, should be made available in the report, so that those seeking advice could do so easily. ST suggested that a comparison between data completeness for older and younger patients would be beneficial.

Action 07/03-04: KC/NCRAS will explore why some Trusts are recorded as diagnosing fewer than 30 patients a year and report back to the PT.

Action 07/03-05: The PT will consider the feedback provided by the CSG on the presentation of case studies, and implement changes to address key points as appropriate.

c) Diagnosis and supportive care:

- The PT described the changes to chapter 5 of the annual report. To date, there has not been a single data item indicating same day triple diagnostic assessment. This will now be added as a data item to COSD V9. The 2019 report will report on women diagnosed in 2017.
- The data for women seen by a breast CNS/named key worker was reviewed. 95% of patients, with data on CNS contact, had contact with a breast CNS reported, however DF felt that 1 in 10 older women not seeing a breast cancer nurse is not satisfactory. KH stated that this may be due to data entry issues and suggested, in the future, investigating the difference between older and younger breast cancer patients, to identify any age discrimination.

- d) Ductal carcinoma in situ (DCIS) and early invasive breast cancer:
- The 2018 annual report contained a brief overview of treatment for DCIS, but the 2019 report contains more detail. The group reviewed the two funnel plots showing the risk-adjusted rates of surgery for DCIS across NHS organisations (50-69 years and 70+ years).
 - The CSG discussed recommendation concerning the management of DCIS in older women. IK suggested that not only should women be given enough information about radiotherapy treatment, they should also be given enough information about the pros and cons of receiving radiotherapy treatment.
 - When discussing early invasive breast cancer, KH noted that regardless of fitness, the numbers receiving surgery decrease when the patient is 70+ years old.

Action 07/03-06: KH noted that there are lower volumes of 70+ year old patients having surgery and stated that the PT will continue to explore why this may be the case.

- e) Fitness assessment form for older patients in breast clinic pilot:
- KH described the fitness assessment form. In the previous meeting, it was suggested that it may save time and improve patient comfort to have a tick box, early on in the form, for patients with an existing diagnosis of dementia. This has now been added to the form. Furthermore, all sections found in the form have been added as items to COSD V9.
- f) Executive summary, including recommendations and infographics:
- The 2019 executive summary has been reduced from 5 pages to 3, with the aim of reducing it further. Furthermore, the recommendations have been refined.
 - IK suggested that a strapline be added the cover of the report. That it may be beneficial to highlight the key points of the document. E.g. “Critical information gaps, good practice/varying practice, and a plan for action”. The PT will look into this.

Action 07/03-07: The PT will consider the feedback provided by the CSG, on the content of the 2019 Annual Report, and implement changes to address key points as appropriate (in the final/Draft 2 of the report).

- g) NHS Organisational tables:
- As in 2018, the 2019 NHS organisational tables are to be published alongside the annual, and clearly signposted.

Action 07/03-08: The PT will seek feedback from the CSG and other key stakeholders on the 2019 NHS organisational tables, to ensure the summaries of information are clear and user-friendly.

6. Project Overview

- a) Highlights since November 2018:
- Datasets: The English datasets were provided on 20 December 2018 to produce the 1st draft of the 2019 annual report by 20 February 2019. Review of the NCRAS datasets highlighted some unexpected issues, which were explored with NCRAS. Two corrected datasets were received in January 2019 and a further three updated datasets are to be received in late February/early March.
 - NABCOP 2019 Annual Report: NABCOP delivered the first draft of the NABCOP 2019 Annual Report to HQIP on 20 February 2019. The CSG and PB are providing feedback on this. HQIP are due to receive the second draft on 22 March. The PT aims to publish the final report on 13 May 2019 at the Association of Breast Surgery AGM (ABS) conference. This is dependent on receiving clearance from the funders, NHS England. In the event that clearance is not received in time, NABCOP are to have all presentation slides to be used at the conference, signed-off by NHS England in advance.
 - NABCOP Tender Extension: NABCOP and HQIP have finalised and signed the contract to “enter into a 24-month extension with the Royal College of Surgeons for the National Audit of Breast Cancer in Older Patients, via a Deed of Variation/Extension to cover the period 1 April 2019 – 31 March 2021.”
- b) Update on collaborations: GIRFT, COP and CQC:
- GIRFT: 48 visits out of 132 have taken place. The GIRFT data analyst embedded in NCRAS has resigned, so there is some hiatus in linking GIRFT breast surgery to any cancer data.

National report writing: There is unlikely to be any cancer data (due to said hiatus), so the focus will remain on breast surgery in its totality. GIRFT are currently developing key themes and recommendations around unwanted radiation and undesirable outcomes. Little of the data is directly linked to age, but it will provide data on reconstruction rates by age (<50yrs, 50-70 and >70yrs).

Developing cross cutting themes: procurement and safe introduction of the new devices, GIRFT and the private sector, standardising OPCS codes for breast interventions.

- COP: NABCOP plan to publish key outcomes from the 2018 AR in April 2019. The proposed metrics for this will be: '% patients receiving a triple diagnostic assessment in a single visit' and '% patients seen by a breast clinical nurse specialist'.
- CQC: NABCOP have collaborated with the CQC to publish the same 2018 metrics (as for COP), and have agreed the related data slides for CQC Trust inspectors. In addition, the CQC slides report on four data quality metrics (ER +, HER 2, TNM status and performance status).

7. Publication of 2018 Outputs

a) Challenges to publication at the ABS Conference – 13 May 2019. Including new NHS England/HQIP Standard Reporting Procedure (SRP):

- ABS Conference: Two abstracts submitted for the conference were accepted for oral presentation. The PT will also prepare an audit update, to be presented by KH – these slides will need to be signed off by HQIP/NHSE at least 1 month in advance of the conference.
- Communicating key messages to NHS trusts/local health boards: A communication and dissemination activity document, containing all NABCOP activity from 2017 to the present day, was discussed. The PT are aiming to increase their activities, and so JM requested that each member of the CSG commit to spreading findings further. One way to do this might be by re-Tweeting NABCOP posts, sharing newsletters, using slides at local meetings. KH suggested that each member of CSG complete one action to share NABCOP activity and then contact JM to notify her of this. DF requested that the PT create a short set of slides to be available for use at local meetings.

Action: 07/03-09: The PT will create a set of presentation slides for the NABCOP update at the ABS conference, to be signed off by HQIP/NHSE at least 1 month prior to the conference.

Action: 07/03-10: Each CSG member is to complete one action to share NABCOP activity, and then contact JM to notify her of this.

Action: 07/03-11: PT are to develop a short set of slides to be available for use at local meetings.

b) Publication of public and patient version

- The PT are aiming to publish the public and patient version either at the same time as the Annual report, or as soon after as possible.

Action: 07/03-12: The PT will seek input from the CSG's patient representatives and patient advocates to draft the public and patient version of the 2019 AR.

8. Ambitions for the audit

- KH briefly described the content of a short document, shared with the group, detailing the ambitions for the audit. We would value the CSG's input into the next draft of this.

Action 07/03-13: The PT will circulate a copy of the 'Ambitions' document with the minutes of this meeting. The PT would be grateful for feedback from the CSG on this document.

7. Suggested date of next meeting

- Thursday 28 November 2019 11:00-13:00 at the Royal College of Surgeons of England.

Actions from Clinical Steering Group meeting: 7 March 2019	Owner	Due Date
Action 07/03-01: The PT will update the CSG on progress working with NCRAS to specify items for NABCOP to be included in COSD V9.	PT	28/11/19
Action 07/03-02: The PT will consider the feedback provided by the CSG on the 'How to read and understand the report' document, and continue to explore how it can best support the 2019 AR.	PT	13/05/19*
Action 07/03-03: The PT will circulate a copy of the 'How to read and understand the report' document with the minutes of this meeting. The PT would be grateful for feedback from the CSG on this document.	CSG	01/05/19
Action 07/03-04: KC/NCRAS will explore why some Trusts are recorded as diagnosing fewer than 30 patients a year and report back to the PT.	KC	13/05/19*
Action 07/03-05: The PT will consider the feedback provided by the CSG on the presentation of case studies, and implement changes to address key points as appropriate.	PT	13/05/19*
Action 07/03-06: KH noted that there are lower volumes of 70+ year old patients having surgery and stated that the PT will continue to explore why this may be the case.	KH	28/11/19
Action 07/03-07: The PT will consider the feedback provided by the CSG, on the content of the 2019 Annual Report, and implement changes to address key points as appropriate (in the final/Draft 2 of the report).	PT	22/03/19
Action 07/03-08: The PT will seek feedback from the CSG and other key stakeholders on the 2019 NHS organisational tables, to ensure the summaries of information are clear and user-friendly.	PT	Ongoing
Action: 07/03-09: The PT will create a set of presentation slides for the NABCOP update at the ABS conference, to be signed off by HQIP/NHSE at least 1 month prior to the conference.	PT	05/04/19
Action: 07/03-10: Each CSG member is to complete one action to share NABCOP activity, and then contact JM to notify her of this.	CSG	31/05/19
Action: 07/03-11: PT are to develop a short set of slides to be available for use at local meetings.	PT	Ongoing
Action 07/03-12: The PT will circulate a copy of the 'Ambitions' document with the minutes of this meeting. The PT would be grateful for feedback from the CSG on this document.	PT	28/11/19
Action: 07/03-13: The PT will seek input from the CSG's patient representatives and patient advocates to draft the public and patient version of the 2019 AR.	PT & CSG	13/05/19

*Anticipated publication date of the NABCOP 2019 Annual Report, at the 2019 ABS Conference.

Catherine Foster

CEU Research Coordinator | T: 020 7869 6139 | E: nabcop@rcseng.ac.uk | W: www.nabcop.org.uk