National Audit of Breast Cancer in Older Patients (NABCOP)
Clinical Steering Group Meeting

Monday 11th June 2018, 11:00-13:00
Research Board Room, Royal College of Surgeons of England

UNCONFIRMED MEETING MINUTES

Present:

Kieran Horgan (Chair)	David Dodwell	Eluned Hughes
Karen Clements	Pat Fairbrother	Yasmin Jauhari
David Cromwell	Catherine Foster	Ian Kunkler (by TC)
Marianne Dillon	Melissa Gannon	Jibby Medina

Apologies:

Deborah Fenlon	Emma Pennery	Richard Simcock
Ashu Gandhi	Stanley Ralph	Sophia Turner
Margot Gosney	Tom Robinson	Maggie Wilcox
Lis Grimsey	Nisha Sharma	Lynda Wyld
Jackie Jenkins		

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). Apologies were given for those unable to attend. IK joined by phone.
- Pat Fairbrother was welcomed as a patient representative and a new member of the NABCOP CSG.

2. **Declaration of any conflict of interest**

- None at this time.

3. **Minutes of the last Clinical Steering Group Meeting on 28 February 2018, and Matters arising**

- The 28th February 2018 meeting minutes were reviewed and accepted as a true and accurate record of the meeting. The only action outstanding was to congratulate Trusts and Health Boards with particularly good data quality (Action 28/02-04). A plan for this is in place and due to be implemented.
- JM was hoping to present a copy of the final Annual Report but this is still awaiting signoff from NHS England.

Action 11/06-01: JM to correct the February 2018 minutes title, updating '28th October 2018' to '28th February 2018'.

4. **Clinical Steering Group Membership**

- PF has joined the group as a new patient representative for Independent Cancer Patients' Voice.

5. Project Overview

5.a Highlights from the past 4 months

- The final draft for the annual report was circulated to HQIP and the CSG to receive feedback. Planning is underway for communications around launching the report at the ABS conference next week. Varied feedback was received, specifically regarding the context for the patient/public version.
- The team had a meeting with CQC regarding breast cancer indicators and they are now trying to narrow these down to five.
- Conversations have also been had with NCRAS and Wales regarding the data for the next annual report; due to the tighter deadline line, the first draft of the report will need to be finished in early February 2019.
- GDPR requirements have been fulfilled, including updates to the webpage, privacy policy and opt-out notices.
- The project team are preparing for publication of the report next week.

5.b NABCOP 2018 Annual Report

- KH presented some of the report's main findings to the group.

I. Publication at the ABS Conference

- The report is due to be launched at the ABS conference on 18th June 2018; this will be an online publication but hard copies are available (contact JM).
- The release of the report will be highlighted through social media, with a newsletter also circulated.
- KH will be presenting the main findings from the report at the conference; MG and YJ also have talks and a poster presentation.
- NABCOP will have a stand to publicise the audit and the report, as well as looking to interact with users to:
    - ask for suggestions about presenting the report on the website
    - collect feedback on what helps trusts with collecting data
    - seek volunteers to be pilot sites for the frailty measure
    - provide information on data flows and analysis timelines with some explanation for time lags (i.e. reporting on 2014-2016 data)

II. Public and patient version – July 2018

- The team want to put a good amount of work into the P&P version of the 2018 annual report, involving Plain English and designers; publication is therefore likely to be in August.
- Once the draft is complete, feedback will be requested from the CSG.
- JM talked through an overview of the report content as well as feedback received from patient representatives.
- It was suggested that the report include a reference to the usemydata.org resource. A tool for patients wanting to voice their support of patient data being used for research, audit and analysis; and in this way support improved data quality.

Action 11/06-02: JM to circulate the public and patient version of the annual report when available.

III. Taking the recommendations forward

- MG highlighted the recommendations made within the 2018 annual report with the group (as circulated prior to the meeting).

- The CSG discussed how each one might be adhered to in practice, including understanding mechanisms for good data completeness.
- IK suggested the recommendation for radiotherapy in women who received BCS for DCIS might be better clarified as "BCS for non-low-risk DCIS". The project team agreed to consider this clarification. If not possible to make it for the 2018 Annual Report (due to be published a week later), then when re-visiting the Radiotherapy dataset and expanding the chapter for the 2019 Annual Report.

Action 11/06-03: The project team are to take on board all feedback provided by the CSG, on the taking the recommendations forward, in the months following the publication of the 2018 Annual Report.

IV. Supporting quality improvement

- The team are considering how NHS organisations can access current information on data completeness as the audit's data is for previous years. One source for English NHS organisations is CancerStats, which uses up-to-date COSD information.
- KC talked the group through the CancerStats site; Level Two of Cancerstats is ready to go on the website and Level Three is being worked up. IK suggested producing a colour coded map which highlights regions with good data completeness and altering 'must' in the recommendations to bold font for emphasis. MD felt that there may be a problem with getting the MDT to complete data properly.
- KH suggested that when looking at systematic cancer assessment, the first date seen and date of biopsy would be reasonable suggestions for estimation if triple assessment had happened on the same day. DD suggested that it may be useful to make a list of what is collected with cancer waiting times if possible to use.
- KH suggested that 'surgery should be considered for all and particular attention given to older patients with minimal comorbidity and frailty measure' should be incorporated into the report recommendations.
- KH talked about the recommendation to Professional stakeholder organisations in relation to the frailty measure and plan to pilot a frailty-comorbidity assessment form in the 70+ ages within willing NHS sites.

Action 11/06-04: KC to check with Jackie Charman (analyst at NCRAS) as to whether it would add value to the NABCOP to request the Cancer Waiting Times dataset.

Action 11/06-05: Based on the CSG's input, it was agreed that an amendment to the recommendations in the report should be made to reflect that 'surgery should be considered for all and particular attention given to older patients with minimal comorbidity and frailty measure'.

V. Presentation on website / dashboard

- The group considered whether having quality improvement tools on the NABCOP website was useful. This might include having organisation-level run charts to use.
- DC described the NHS improvement site to the group, specifically:
    - does anyone working in the NHS have sufficient time to look at these pages and/or find them useful
    - would such tools encourage trusts to stick to recommendations or would an alternative route would be better
- IK raised that there is a lacking in highlighting trusts that provide the least complete data and questioned whether doing this would motivate improvement.
- DC added that highlighting the top ten gives way to the bottom learning from the top. Also highlighting the top rather than the bottom ten reduces the chance of replicating GIRFT.

- IK suggested that an online tool for highlighting a particular trusts ranking would be useful. KC added that data improvement leads with NCRAS need to be utilised and suggested she speak to Karen Graham about how best to highlight trusts.
- It was suggested that sending letters to bottom trusts may encourage improvement however, KH advised that this could lead to trusts wanting knowledge of how robust the data is; NABCOP feel that they are making improvement in data robustness but are not yet at the stage to do this.
- DD raised that it is unfortunate that at trust level, improvement only happens when there is a scandal or a financial driver. It would be hoped that the aim is to get clinical teams to engage in data and reverse negative data attitudes. DC added that trusts seem to be listening to GIRFT, partly due to financial issues.

Action 6/11-06: KC to speak to Karen Graham (NCRAS data liaison officer) regarding how best to highlight and reach out to top/bottom NABCOP NHS trusts.

5.c Collaborations: GIRFT and CQC

- KH confirmed that NABCOP and GIRFT continue to work collaboratively and share salient information, to ensure no duplication of efforts by either initiative; and ensure minimal additional burden for participating Trusts.
- NABCOP looks forward to the outcome of GIRTS scheduled visits in 2018.

Action 6/11-07: NABCOP will share key materials and outputs from our upcoming publications with GIRFT, in the event of these being useful materials for GIRFT visits.

6. NABCOP 2019 Annual Report – 1st draft due mid-February 2019

6.a. Ideas for next report

- Work will soon start on the next annual report to produce a first draft for HQIP mid-February; for publication in May 2016 to coincide with the 2019 ABS conference.
- The team are currently in conversations with NCRAS about receiving a snap shot of the English data in September to begin work on and to see the new version of COSD data.
- Full data for publication should be ideally received in December; this will be flagged as this leaves minimal time to analyse final data for a mid-February deadline.
- Welsh data is to be received in October.
- The 2019 annual report will consider and move on from those limitations found in the 2018 annual report.

6.b. Frailty Work

- YJ presented the frailty methodology, used within the audit, based on the electronic Frailty Index (eFI); confirming the group are happy for this same methodology be used in further work. There was no objection; KH will contact those absent asking for comments on the methodology.
- There was some discussion around patient consent in frailty measuring and the need to keep the patient fully informed in decision making.
- KH introduced the frailty-comorbidity assessment form that was constructed during the subgroup in December 2017 (circulated to the group). The aim is that when a patient is 70 years or older and is first seen in clinic at their triple diagnostic assessment, this form will be filled in. The form will then be available at the first diagnostic MDT meeting when treatment planning begins. The form was trialled in Leeds and was found to be easy to use, however, there was some clinical embarrassment in asking some of the questions on the Abbreviated Mental Test to perceived mentally well patients. With some adjustments, the hope is that this form could be included as collected data items within COSD.

- IK questioned as to whether the frailty-comorbidity assessment form would be filled in by nurses or clinicians; KH responded that in the early days of use, it would be beneficial for clinicians to be involved in order for them to give feedback on the form.
- KC was asked to speak with Andy Murphy re: including the frailty assessment items within COSD.
- KC asked whether this assessment would be relevant to all cancers. KH confirmed that it could be relevant to other groups but the form needs to be more established first.
- IK commented that the images for very severely frail and terminally ill on the frailty score do not correspond with the text and could lead to frightening early diagnosed patients. He suggested removing the image for terminally ill and KH agreed this could be explored.

Action 11/06-08: KH to contact absent CSG members for comments on frailty methodology.
Action 11/06-09: KC to speak with Andy Murphy re: including the frailty assessment items within COSD.
Action 11/06-10: PT to explore removing image from terminally ill category in the Clinical Frailty Scale.

6.c. Outcomes to be covered

- CSG input will be requested on the following planned outcomes: mortality up to 3 years; completion of chemotherapy regimen; re-excision rates; emergency re-admission during treatment.

6.d. Cancer Patient Experience Survey (CPES) aspects to explore

- The 2015 version of the Cancer Patient Experience Survey was circulated to the group; 2015 data is the first year of available data that will link to the cohort. JB asked the group if anyone had used this data before.
- MD asked how these surveys are distributed, as in Wales patients with cancer have been randomly picked during their stay within a hospital, but the stay may not have not been related to their cancer; JM is to investigate this.
- PF queried the lack of CPES questions regarding research and expanding; she is approaching patient support groups to understand whether they want research questions expanded. PF commented that she likes that patients are asked about their understanding.

Action 11/06-11: JM to explore how patients are approached to be included in the CPES.

7. Any other business

None.

8. Date of next meeting

Monday 26 November 2018 11:00-13:00 at the Royal College of Surgeons of England.
Action 11/06-12: JM to send out an Outlook calendar invitation to the next Clinical Steering Group meeting.

Actions from Clinical Steering Group meeting: 11 June 2018	Owner	Due Date
Action 11/06-01: JM to correct the February 2018 minutes title, updating '28th October 2018' to '28th February 2018'.	JM	11/07/2018
Action 11/06-02: JM to circulate the public and patient version of the annual report when available.	JM	31/08/2018
Action 11/06-03: The project team are to take on board all feedback provided by the CSG, on the taking the recommendations forward, in the months following the publication of the 2018 Annual Report.	PT	Ongoing
Action 11/06-04: KC to check with Jackie Charman (analyst at NCRAS) as to whether it would add value to the NABCOP to request the Cancer Waiting Times dataset.	KC	16/11/2018
Action 11/06-05: Based on the CSG's input, it was agreed that an amendment to the recommendations in the report should be made to reflect that 'surgery should be considered for all and particular attention given to older patients with minimal comorbidity and frailty measure'.	JM	18/07/2018
Action 6/11-06: KC to speak to Karen Graham (NCRAS data liaison officer) regarding how best to highlight and reach out to top/bottom NABCOP NHS trusts.	KC	16/11/2018
Action 6/11-07: NABCOP will share key materials and outputs from our upcoming publications with GIRFT, in the event of these being useful materials for GIRFT visits.	PT	Ongoing
Action 11/06-08: KH to contact absent CSG members for comments on frailty methodology.	KH	16/11/2018
Action 11/06-09: KC to speak with Andy Murphy re: including the frailty assessment items within COSD.	KC	16/11/2018
Action 11/06-10: PT to explore removing image from terminally ill category in the Clinical Frailty Scale.	PT	16/11/2018
Action 11/06-11: JM to explore how patients are approached to be included in the CPES.	JM	16/11/2018
Action 11/06-12: JM to send out an Outlook calendar invitation to the next Clinical Steering Group meeting.	JM	16/11/2018

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