

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

**26<sup>th</sup> November 2018, 11am-1pm  
Research Board Room, Royal College of Surgeons of England**

**UNCONFIRMED MEETING MINUTES**

**Present:**

Kieran Horgan (Chair)	Margot Gosney (by TC)	Stanley Ralph
Karen Clements	Eluned Hughes	Alistair Ring
David Cromwell	Yasmin Jauhari	Tom Robinson (by TC)
David Dodwell	Ian Kunkler	Richard Simcock
Deborah Fenlon	Fiona MacNeill	Sophia Turner
Catherine Foster	Jibby Medina	Maggie Wilcox
Ashu Gandhi	Andrew Murphy	Lynda Wylde
Melissa Gannon	Emma Pennery	

**Apologies:**

Marianne Dillon	Lis Grimsey	Jacquie Jenkins
Pat Fairbrother	Chris Holcombe	Nisha Sharma

**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 introduced the aims and objectives of the NABCOP CSG.

**2. Declaration of any conflict of interest (standing item)**

- None at this time

**3. Minutes of the last Clinical Steering Group meeting on the 11 June 2018, and matters arising**

- The 11th June 2018 meeting minutes were reviewed and accepted as a true and accurate record of the meeting.

**Action 26/11-01:** In discussions around the English dataset used by NABCOP, KH highlighted that there is currently no data item for recording whether triple assessment occurred on the same day, and so recording cancer waiting times (specifically date seen) may be useful for trusts. AM suggested attempting to add a triple assessment data item to Cancer Outcomes and Services Dataset (COSD). The Project Team (PT) and KC will continue to explore the collected items and refine the data specification, and maintain ongoing dialogue with AM regarding potential additions to COSD data collection.

**4. Clinical Steering Group membership**

- MW will be stepping down as one of the patient representatives for Independent Cancer Patients' Voice. KH took the opportunity to thank MW for her valuable contribution as a member of the CSG over the last 3 years. We have valued her involvement and will miss her input going forwards.

**Action 26/11-02:** MW will recommend someone to join the CSG (and PB) in her place, as a patient representative for Independent Cancer Patients' Voice.

## 5. Project Overview

### a) Highlights from the past 5 months:

- The datasets for the next report have been agreed with NCRAS and the Wales Cancer Network. The whole Welsh dataset and an early snapshot of the English dataset have been received to start putting together analyses for the 2019 Annual Report.
- In October, a tender extension meeting took place with HQIP and a letter of intent to fund the RCS to continue as audit provider for a further 2 years was received in early November. The next step is to agree the deliverables for the coming two years.
- Recent online publications produced by the NABCOP team: A data specification for the Welsh dataset / Canisc; tabulated summaries of the Annual Report Tables; and the Public and Patients versions of the Annual Report – with valuable input from a CSG subgroup.
- The drafting of the 2019 Annual Report has started, and KH asked the group to consider how the audit should now be directed to most benefit older patients with breast cancer.

**Action 30/11-03:** The PT will follow up by email with the CDG CSG when circulating the minutes to ask: What benefit should the audit seek to produce / provide? What problems experienced by clinicians, in practice could the audit seek to address?

### b) Published NABCOP 2018 Annual Report(s):

- MW feedback that the Annual Report NHS Organisation Tables (published online) were useful but should be made more available to the public. A further suggestion was made that using a traffic light motif for highlighting incomplete data would be useful.

**Action 30/11-04:** MW suggested that, to improve patients' confidence, it would be beneficial to highlight patient input earlier in both the full and patient versions of the annual report. The PT will aim to do this.

**Action 30/11-05:** The PT will seek feedback from members of the CSG, including AG and FM, next year on the re-development of the online NHS Organisation Tables. The PT will aim to produce an easy to access (few clicks) set of summary results by NHS Organisation (such as an A4 summary). The ultimate outcome is to refine the website to allow clinical staff and patients to search for audit results by NHS Organisation.

### c) CancerStats and Somerset Cancer Registry (SCR):

- Level 2 reports have gone live on CancerStats. These allow English NHS trusts to review the data quality of 20 specific key data items. KH highlighted that there are still large gaps in complete data returns for some items. AM commented that they currently have liaison officers working with MDTs to help them in providing items such as pre-treatment staging data. A request was made by FM for the 'died within a year of diagnosis' metric to be clarified because this refers to the older patient dying from conditions other than breast cancer.
- Quarterly Data Completeness Reports have gone live on CancerStats and the project team are awaiting feedback on how useful NHS trusts find them. These reports look at four metrics (TNM, Performance Status, Treatment Start Date and Clinical Nurse Specialist seen); all of which have been set with an aspirational target of 90% expected completeness. KH highlighted that completeness for 'Treatment Start Date' is very good and suggested that this is due to this information already being incorporated into trust mechanisms. He went on to question whether a similar system to be useful for raising completeness in other metrics.

- d) Collaborations: GIRFT, COP and CQC:
- GIRFT: FM introduced the aims and objectives of GIRFT and presented some of the work completed so far. 35/132 trusts have been visited and GIRFT are due to produce a national report in Autumn 2019. IR suggested that the GIRFT findings need to be brought to a wider audience, potentially a breast cancer day with Breast Cancer Now. AG highlighted that there will be several sessions devoted to this at the ABS conference in May, with one session specifically devoted to GIRFT, NABCOP and screening data. FM discussed the difficulties they have found in NHS trusts not viewing their NABCOP data prior to GIRFT visits. As Trusts are very busy, FM suggested that it would be helpful for GIRFT to receive individual trust level data two weeks prior to their visit, in the form of a data pack. FM suggested to share a GIRFT data pack to see how it may align with a NABCOP pack. DC highlighted that NABCOP are currently doing this with the tabulated summaries for the Annual Report, but these may need further publicising.
  - COP: NABCOP are currently working with HQIP on implementing the COP, and plan to publish key outcomes from the 2018 Annual Report in early 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 are collaborating with the CQC to produce some 2018 data slides for their trusts inspectors. The same metrics as with COP are to be used with the addition of four QI metrics (ER +, HER2, TNM status and performance status).
- e) Challenges to publication at the ABS Conference: The first draft of the annual report is to be submitted to HQIP in February 2019, with publication due for the ABS conference in May. Due to tight timelines, the CSG may not have time to report back on drafts and so KH requested the group to provide report feedback as early as possible.
- Action 26/11-06:** CSG members are to provide prompt feedback on the 2019 Annual Report, once the 1<sup>st</sup> draft is delivered in mid-February.

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

- a) Datasets:
- i. Collaboration with NCRAS to receive English datasets incl. Cancer Patients Experience Survey (CPES) data: MG highlighted to the group some of the changes for the 2019 report and explained some of the ways that the four year datasets will be used. She then went on to remind the group of the patient cohort for 2019.
  - ii. Collaboration with NHS Wales to receive Welsh datasets: This is ongoing, and completed for 2019.
- b) CSG input on content based on 2018 report – including outcomes to cover and key guidance:
- Seen by breast CNS/named key worker: Data will now be available for both English and Welsh Patients. This indicator will report on the most recent year of diagnosis available (women diagnosed in 2017) with a view to seeing if this has improved over time. KH suggested that CNS viewing the data may encourage the improvement of reporting, as most cases patients are seen by a CNS. AM questioned whether proper guidance has been provided on how to log this correctly. EM stated that there are some discrepancies in meanings of terms that need to be clarified. KH said that they will try and assist with this and asked the group to highlight any glitches they have come across within their work.
  - Metastatic disease at initial presentation: YJ asked the CSG how best to report this, considering that when reporting older patients there are a higher proportion of women with unrecorded M-stage. LW advised that this fact should be highlighted but the reporting should proceed among women with M1 disease

- Surgical treatment: by tumour characteristics – The 2019 report will report on treatment received by tumour characteristics. KH highlighted that regardless of the DCIS grade, patients look to be receiving the same level of surgery.
  - Chemotherapy: The proposal for 2019 report is a more detailed focus on the use of chemotherapy.
  - 2019 – Year 3 Annual Report: Mortality and patient experience will be covered as additional data in the year 3 report. YJ presented some of the work the team have done looking at survival rates across the four age ranges. FM felt that this would prove useful when providing informed consent and question whether it could be used to enhance the predict dataset. TR questioned as to whether this information would be more useful to patients if presented as an infographic.
  - CPES Data (2015-2016): The team have received the 2015 data, which links to the audit cohort, to include in the 2019 report. It is hoped that 2016 data may also be available to report on. JM presented some preliminary findings from this data. DF highlighted that the older and more frail the patient, the less likely they are to report, therefore the high% percentages may be overestimates . DF also suggested that those with greater frailty are in need of more contact with the CNS, and that this is something that needs to be highlighted in the report. MW suggested the team investigate some patient focused research taking place which looks at follow up appointments. JM to contact MW.
  - A further comment was made that the executive summary is too long.  
**Action 30/11-07:** MW to send JM information on patient focused research on follow up appointments to inform NABCOP's work.  
**Action 30/11-08:** The PT will consider the feedback provided by the CSG, on the content of the Annual Report, and implement changes to address key points as appropriate.
- c) Frailty pilot:
- The frailty sub-group met in December'17 and discussed the experience of measuring frailty by the different specialities e.g. ortho-geriatrics and the features of an 'ideal' fitness assessment. The purpose of a fitness assessment in NABCOP was discussed and two purposes were established: (a) To create a system to trigger the identification of a pre- or frail patient. (b) To identify the 'well' but who are not having surgery.
  - The form was created in three parts: Clinical Frailty Scale, Abbreviated Mental Test Score and a set of two questions to establish if there are any cardiorespiratory disease or significant malignancy. This was piloted in mid-October 2018 for 8 weeks. 16 trusts volunteered to be in the pilot and a handful of trusts have started submitting feedback. The pilot has been positive and the team are wondering how to take this forward. LW has used this assessment and fed back that the patients liked the pictures but questioned as to whether the text was read. LW suggested it would save time and patient comfort to have a tick box, early on, for patients with an existing diagnosis of dementia.  
**Action 30/11-09:** The PT will follow up by email with LW and MG on the matter of assessing / recording a diagnosis of dementia.
- d) Supporting quality improvement: JM asked the group for suggestions (in person or by email) re. Quality Improvement strategies or methods that would be useful to promote, and any feedback on quality improvement initiatives so far.
- 7. Suggested date of next meeting**
- Thursday 7 March 2019 11:00-13:00 at the Royal College of Surgeons of England.

<b>Actions from Clinical Steering Group meeting: 26 November 2018</b>	<b>Owner</b>	<b>Due Date</b>
<b>Action 26/11-01:</b> In discussions around the English dataset used by NABCOP, KH highlighted that there is currently no data item for recording whether triple assessment occurred on the same day, and so recording cancer waiting times (specifically date seen) may be useful for trusts. AM suggested attempting to add a triple assessment data item to COSD. The PT and KC will continue to explore the collected items and refine the data specification, and maintain ongoing dialogue with AM regarding potential additions to COSD data collection.	PT	07/03/19
<b>Action 26/11-02:</b> MW will recommend someone to join the CSG (and PB) in her place, as a patient representative for Independent Cancer Patients' Voice.	MW	07/03/19
<b>Action 30/11-03:</b> The PT will follow up by email with the CDG CSG when circulating the minutes to ask: What benefit should the audit seek to produce / provide? What problems experienced by clinicians, in practice could the audit seek to address?	PT	07/03/19
<b>Action 30/11-04:</b> MW suggested that, to improve patients confidence, it would be beneficial to highlight patient input earlier in both the public and patient versions of the annual report. The PT will aim to do this.	PT	13/05/19
<b>Action 30/11-05:</b> The PT will seek feedback from members of the CSG, including AG and FM, next year on the re-development of the online NHS Organisation Tables; as they provided clear feedback about the need for a personalised formula. The PT will aim to produce an easy to access (few clicks) set of summary results by NHS Organisation (such as an A4 summary). The ultimate outcome is to adapt the website to allow clinical staff and patients to search for results by NHS Organisation.	PT	30/06/19
<b>Action 26/11-06:</b> CSG members are to provide prompt feedback on the 2019 Annual Report, once the 1st draft is delivered in mid-February.	CSG	<b>14/03/19</b>
<b>Action 30/11-07:</b> MW to send JM information on patient focused research on follow up appointments to inform NABCOP's work.	MW	20/02/19
<b>Action 30/11-08:</b> The PT will consider the feedback provided by the CSG, on the content of the Annual Report, and implement changes to address key points as appropriate.	PT	20/02/19
<b>Action 30/11-09:</b> The PT will follow up by email with LW and MG on the matter of assessing / recording a diagnosis of dementia.	YJ & PT	Ongoing

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