

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

Wednesday 4th October 2017, 11am-1pm
Research Board Room, Royal College of Surgeons of England

MEETING MINUTES¹

Present:

Prof Kieran Horgan (Chair)	Mrs Melissa Gannon	Dr Stanley Ralph
Ms Karen Clements	Ms Lis Grimsey	Dr Alistair Ring
Prof David Cromwell	Prof Chris Holcombe	Prof Tom Robinson
Miss Marianne Dillon	Miss Yasmin Jauhari	Ms Maggie Wilcox
Prof David Dodwell	Ms Jibby Medina	Ms Lynda Wyld
Mr Ashu Gandhi	Dr Emma Pennery	

Apologies:

Dr Deborah Fenlon	Prof Ian Kunkler	Dr Nisha Sharma
Prof Margot Gosney	Ms Mairead MacKenzie	Dr Richard Simcock
Ms Eluned Hughes	Mr Andrew Murphy	

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. LW joined by phone.
- Melissa Gannon was welcomed as a new methodologist based within the Clinical Effectiveness Unit, working on NABCOP.
- The group discussed finding a substitute for MM, as she has yet to have been able to attend, with the possibility of having three representatives (and two attending) for Independent Patient Cancer Voice (IPCV).

Action 04/10-01: MW and MM to explore recruiting a third patient representative – to ensure two representatives for IPCV are usually in attendance at CSG meetings – and forward their contact details to JM.

2. Declaration of any conflict of interest

None at this time.

3. Minutes of the last Clinical Steering Group Meeting: 14 December 2016

- The 14 December 2016 meeting minutes were reviewed and no corrections were requested. Minutes were confirmed as correct.
- All actions from the 14 December 2016 meeting were reviewed:
 - The Project team were to formally write to invite Jacquie Jenkins to join the CSG (Action 14/12-02).
 - It was noted that HQIP commended the NABCOP Communication Strategy document as an example of best practice for NCAPOP audits (in relation to Action 14/12-07).
 - KH, DD and YJ have been in contact with Tania Kalsi, Consultant Geriatrician, Guy's & St Thomas' with a special interest in frailty assessment; this is ongoing (Action 14/12-08).

¹ Confirmed February 2018.

- The remaining action points were noted as having been completed with information on some picked up later in the meeting.

Action 04/10-02: KH will formally write to invite Jacquie Jenkins to join the CSG.

4. Matters arising

None at this time.

5. Clinical Steering Group membership

The group reviewed membership for NABCOP.

- Fiona MacNeill, Getting It Right First Time (GIRFT) Breast Cancer (BCa) lead, has been invited to join the CSG. FM met with the Project Team on the 8 September to discuss NABCOP and how to avoid the duplication of efforts, and overburdening participating clinicians/Trusts. AG expected GIRFT to cover clinical issues such as breast implant outcomes; LW suggested there is likely to be limited routine data available for such analysis. MW hopes GIRFT have involvement from patients to ensure messages are consistent and positive. It was also mentioned, in relation to the data sources that might be used by GIRFT that online discussions could be a rich source of information.
- Richard Simcock has been invited to join the CSG (Action 14/12-02); he sent apologies for this meeting.

6. Project overview

a. Audit Aims

KH took the CSG through a reminder of the aims and objectives of the audit, noting that only women were included, with men being beyond the scope as per the HQIP commissioning document. The audit will work with the data already provided to NCRAS, in order to reduce the burden on Trusts. The audit questions addressed by NABCOP may evolve over time to reflect changes in the evidence base and data available.

b. Highlights from the past 9 months

JM took the CSG through the Highlight report (circulated prior to the meeting). There were no suggestions on improving the first **Annual Report**; LW commented that it was well written and very professional. The patient data for the audit has Section 251 approval and team are in the process of cleaning 2014/15 English data from NCRAS. JM highlighted the risks involved around the delivery of the 2016 English data, and Welsh data, but both are due to arrive in Nov/Dec-2017, which will be in time for the publication of the next Annal Report. Its publication was scheduled to coincide with the ABS conference in June 2018.

Concerning **communications and dissemination** TR suggested maximising Tweets to increase engagement with and visibility of NABCOP; the Project team will provide the CSG with any hash tags to use on Twitter as relevant. There was also suggestion of engaging with other charities as well as the ABS. The newsletter is sent to all contacts within Trusts (including those in the Trust to expand the net of recipients as well as ensuring the newsletter is smartphone and tablet compatible. Tweeting when the newsletter is available online may also increase coverage.

Action 04/10-03: JM to double check that all contacts within Trusts (and all CSG and PB members) receive the NABCOP Newsletters (except those who have unsubscribed).

c. Progress with datasets – NCRAS and CaNISC

DC provided the CSG with an update on the next steps to obtaining the Welsh patient-level data. KH asked whether it was possible to link patient experience data to the other datasets; KC noted that this was possible via the unique patient ID and that this data just offers a few months snap shot. It was also noted that the Welsh data is expected to be broadly compatible with the English data items.

d. Preliminary analyses of English data – Data quality and indicators

DC and YJ presented an overview of the datasets and current English patient cohort. There was some discussion about how to handle patients with two tumour records (there were 2,111 patients with multiple tumours). KC will check with NCRAS colleagues and clarify our understanding of these issues.

1. Referral route to diagnosis

DC noted that some patients seem to have multiple referral pathways and asked the CSG whether the idea of a multiple referral route makes sense. AR suggested multiple routes may apply after screening for those patients who then present to the GP as symptomatic. KC will link YJ to someone within NCRAS who can answer that question YJ asked about the ‘high’ numbers in patients over 70 referred via screening. EP was clear that although individuals are no longer invited for screening after this age they can keep attending – KH suggested a comparison with screening audit data could help understand if these numbers correlate.

2. Recorded hormone status (missing ER status)

LW shared an approach used in her studies whereby patients with no ER status but who had anti-oestrogen treatments were coded as ER positive (used as proxy). It was also suggested the Audit team check whether or not a patient missing ER status had hormone therapy. TR confirmed with LW whether this could be a reflection of inaccurate record keeping.

DC asked what can NABCOP do in addition to NCRAS to feedback data quality gaps for Trusts? In addition, should we consider not publishing data for some Trusts based on data quality and not meeting a data quality threshold? TR raised the concept used within the Sentinel Stroke National Audit Programme (SSNAP) of scoring Trusts and highlighting those with poor data quality (this was discussed in more detail later on in the meeting).

KH noted the fact that some registry studies do end up excluding sites if the data is not of a certain quality standard.

3. CNS Involvement

LG and EP commented that this data should be available as patients are being seen by a CNS. KH suggested this data item was a good example of data returns being completely erroneous (Box not being ticked in SCR) and not a reflection of Trusts’ practice. Provision of this figure for feedback may help incentivise Trusts to improve data returns.

EP noted that the patient experience survey tells us 97% have CNS support. It feels important we do capture this information as anecdotally older patients ‘don’t want to bother the nurse’ or feel they are busy with younger patients.

LW highlighted the importance of care in what we report and clearly stating such data is flawed.

DC asked if it was sensible to report (for example) 100% of patients were seen by a CNS when a Trust has only given data on 10% of their total patients. TR suggested the need to allow for data to be corrected, which supports publishing on data completeness.

Action 04/10-04: The project team are to take on board all feedback provided on the preliminary analyses of English data, when progressing the next set of analyses in the upcoming months.

Action 04/10-05: KC will raise a number of questions with colleagues at NCRAS, to address the points raised (as above, throughout Section 6.d) in relation to the data completeness of items used for the preliminary analyses of English data.

e. Timeline to publication

The project timeline was circulated in advance of the meeting. The publication date is now in line with the publication of the next Annual report at the ABS conference.

f. Trust/Health Boards' opportunity to comment on results

Advice was sought on whether or how the Audit could (a) Provide Trusts with their results in advance of publication, (b) allow them the opportunity to comment on the accuracy of the results, and (c) potentially exclude Trusts with data returns below a pre-specified threshold on particular data item(s) was discussed:

- The possibility of providing a chance for Trusts to comment on their results was discussed; considering this feedback mechanism could minimise grievances raised around the presentation of Trusts' data – e.g. as a result of poor data quality and/or completeness. An example from the RCOG, of how this is undertaken within their maternity indicators (and shown online), was described.
- KH suggested the data as received should be what is presented in the Year 2 report. The CSG confirmed they were happy with this approach that “the data is the data”.
- TR provided an example of approach used in SSNAP where a band A-E (10% bands) is assigned based on case ascertainment (number expect vs submitted). For example, where this is less than 60% data is suppressed and given an X; where there is less than 90% the Trust is penalised. Thinking of this application within breast cancer, MD asked whether this would be reliable; and whether or not there are any items that must be 100%. DC commented that to take on this approach we would need thresholds for each indicator.

Action 04/10-06: TR to share details of the SSNAP methodology for reporting on data quality and including/excluding Trust from reports.

- MW emphasised the importance of patient and public involvement, and the role of patients in holding the Trusts accountable for accurate/inaccurate use of their data. Publication of all results may convince the public to put pressure on Trusts to improve data returns.
- Overall, it was felt that, considering NABCOP's timeline and resource level, it would be acceptable to publish the Year 2 report without giving Trusts any ability to add comments. Such an approach would mean the audit should ensure the methodology is explained to Trusts.

g. Subgroups/expert input

The Project Team suggested it would be extremely useful to set up several subgroups of CSG members to consult on specific topics more frequently in the run up to publication. Coordination of these groups will be by the Project Team.

CSG members were asked to enlist or suggest who might be most suitable for each group:

Grp 1 – Assessing frailty, comorbidities, cognition: SR, TR, MGo, LW & LG (Macmillan group) suggested. Meeting Wednesday 13-Dec-2017.

Grp 2 – Data analyses inclusion & exclusion criteria: *Nominate yourself to JM.*

Grp 3 – Presentation of results (E.g. Use of funnel plots, consistency in annual reports): *Nominate yourself to JM.*

Action 04/10-07: Project Team to confirm subgroup membership and set up meetings/teleconferences as appropriate.

7. Any other business

None.

8. Date of next meeting

Wednesday 28 February 2018 11:00-13:00 at the Royal College of Surgeons of England.

Actions from Clinical Steering Group meeting: 04 October 2017	Owner	Due Date
Action 04/10-01: MW and MM are to recruit a third patient representative – to ensure two representatives for IPCV are usually in attendance at CSG meetings – and forward their contact details to JM.	MW	17 Jan 2018 (6 wks prior to next CSG)
Action 04/10-02: KH will formally write to invite Jacquie Jenkins to join the CSG.	KH	17 Jan 2018
Action 04/10-03: JM to double check that <u>all</u> contacts within Trusts (and all CSG and PB members) receive the NABCOP Newsletters (except those who have unsubscribed).	JM	1 Dec 2017
Action 04/10-04: The project team are to take on board all feedback provided on the preliminary analyses of English data, when progressing the next set of analyses in the upcoming months.	Project Team	3 Jan 2018
Action 04/10-05: KC will raise a number of questions with colleagues at NCRAS, to address the points raised (as above, throughout Section 6.d) in relation to the data completeness of items used for the preliminary analyses of English data.	KC	1 Nov 2017
Action 04/10-06: TR to share details of the SSNAP methodology for reporting on data quality and including/excluding Trust from reports.	TR	1 Nov 2017
Action 04/10-07: Project Team to confirm subgroup membership and set up meetings/teleconferences as appropriate.	Project Team	6 Nov 2017

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