



palliative care
outcomes collaboration



PCOC Data Policy

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PCOC data policy

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Approved by:	PCOC Executive Directors Group				
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Supporting documents	<ul style="list-style-type: none"> ▪ PCOC outcomes data dictionary and technical guidelines ▪ PCOC profile collection data dictionary and technical guidelines ▪ PCOC residential aged care data dictionary and technical guidelines ▪ PCOC registration form ▪ PCOC user agreement ▪ PCOC clinical manual ▪ PCOC application for access and use of PCOC data for research purposes ▪ Australian code of responsible conduct of research ▪ Principles for accessing and using publicly funded data for health research ▪ Australian health services research institute (AHSRI) policy for seeking ethical approval for research ▪ National statement on ethical conduct in human research (2007, Updated 2018) ▪ PCOC data linkage technical guidelines and procedure 				

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Terms and definitions

Terms and definitions used throughout the PCOC Data policy are listed in the table below. The terms are defined as they relate to PCOC and may have a different meaning when applied to other settings.

Terms	Definitions
Aggregate data	Manipulation of separate sets of data by totalling the number of cases meeting specific criteria, or summing data items for specific subpopulations
AHSRI	Australian Health Services Research Institute
Data custodian	The entity that collects or generates data for any purpose, and is accountable and responsible for the governance of that data
Data dictionary and technical guidelines	A document that outlines the data items, their definitions and validation rules to be collected as part of the PCOC dataset
Dataset	A collection of data
Data linkage	The joining of one or more data sets through key variables common to each of the data sets being linked. Also referred to as data integration
Data release	Making data publicly available with no or few restrictions on who may access the data and what they may do with it
Data sharing	Data sharing is making data available to another agency, organisation or person under agreed conditions
Data sharing agreement	A formal arrangement between a data custodian and another entity, organisation or individual that details conditions under which data is shared and used
Disclosure risk	The combination of likelihood and consequence that information about an individual, organisation or other entity is revealed or provided to an unauthorised person or entity
HREC	Human Research Ethics Committee
PCOC longitudinal database	All data submitted by services participating in PCOC since PCOC commenced up until the present
PCOC staff	All staff employed and collaborating with AHSRI either in a paid, honorary or voluntary manner. This includes PCOC's chief investigators, executive director, director, quality and education staff, data and statistical staff, improvement facilitators and administrative staff.
Research data	Non-identifiable extracts of either unit record data or aggregate data taken from the PCOC longitudinal database for use in research
Services participating in PCOC	Palliative care services who are registered with PCOC
Unit record data	Records that relate to an individual who has commenced an episode of care (according to the PCOC definition in the PCOC Data Dictionary and Technical Guidelines) with a service participating in PCOC

About the PCOC data policy

Background to PCOC data policy

1. PCOC is a national program that uses standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. PCOC aims to systematically improve palliative care patient and carer outcomes, including pain, symptom control and psychosocial distress. Led from Australia, PCOC collaborates with international partners. Participation of services in PCOC is voluntary and assists palliative care service providers to improve practice.

Central to the program is a framework and protocol for routine clinical assessment and response. This works in parallel with a routine point-of-care data collection, capturing clinically meaningful information in settings where palliative care is provided. The items in the PCOC data collection:

- Provide clinicians and others with an approach to systematically assess individual patient experiences
- Include routine patient-reported outcome measures (PROMs), patient-reported experience measures (PREMS) and clinician-rated measures
- Define a common clinical language to allow palliative care providers to communicate with each other, and
- Facilitate the routine collection of consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement at service, state and territory, and national and international levels.

PCOC is a national collaboration delivered by a partnership of four university research centres including: the University of Wollongong (UOW), Queensland University of Technology (QUT), University of Western Australia (UWA) and the University of Technology (UTS) Sydney.

The PCOC data policy was developed in consultation with services participating in PCOC, data analysts, researchers and other stakeholders, and with reference to other national outcome centres, including the Australasian Rehabilitation Outcome Centre (AROC) and the electronic Persistent Pain Outcomes Collaboration (ePPOC).

Purpose of the policy

2. This policy sets out the principles, guidelines and procedures that govern the data collected and held by PCOC and the use of those data.
3. The policy is instrumental in communicating the principles and intentions of PCOC both internally and with services participating in PCOC members and other stakeholders.
4. PCOC guidelines, agreements and forms, and technical documents regarding the collection and use of data are to be used in conjunction with this data policy.

Policy principles

5. Data submitted to and managed by PCOC is used for reporting, benchmarking and research into areas of importance to the palliative care sector.

6. Services participating in PCOC are the original custodians of the data they supply to PCOC and retain ownership of the intellectual property relating to those data.
7. The Australian Health Services Research Institute (AHSRI) is the custodian of the PCOC longitudinal database and owner of the intellectual property relating to the PCOC longitudinal database.
8. AHSRI does not share any aggregated or unit record data from an individual service participating in PCOC, unless provided with written consent from the service.
9. Non-identifiable extracts from the PCOC longitudinal database can be released for use in research after approval of a formal application to PCOC (Application for access and use of PCOC data for research purposes).
10. The value of data lies in its use. Use of datasets for research and quality improvement should be promoted, encouraged and maximised for public benefit, while also protecting privacy and confidentiality.
11. Research and quality improvement is an important endeavour to drive improvements for the benefit of individuals requiring palliative care, their families, society and systems.
12. The provision of data to PCOC and the sharing of the PCOC data is done with the intent to contribute to the generation of knowledge, improved practice and policy.
13. Linking PCOC data enables valuable information for policy and research into the health and wellbeing of the population.
14. The sharing of high-quality data support high-quality outputs. Only data items of a sufficiently high-quality are shared.
15. PCOC is committed to ensuring privacy principles. PCOC releases the least sensitive level and number of data items practicable to fulfil the requirements of the research proposal.
16. PCOC's data policy will be revised in order for it to remain contemporaneous in line with advances in palliative care, and data, research and health technologies.
17. Specific conditions apply to the reporting and publication of PCOC data, including submission of pre-publication drafts of any derivative works to the PCOC Director for review by PCOC and potential advice on data interpretation.
18. This policy should be read in conjunction with the supporting documents listed previously.

Application and scope

19. All PCOC staff, services participating in PCOC and those that have access to PCOC data are required to comply with the policy and be familiar with its content and aware of their responsibilities and obligations.

Exceptions

20. This policy does not apply to data that are not part of the PCOC dataset.

Governance and ownership in relation to the data policy

PCOC's governance

21. PCOC's Management Advisory Board (MAB) is the primary governance committee for PCOC, as agreed under the Funding Agreement with the Australian Government Department of Health.
22. PCOC's Executive Directors Group (EDG) reports to PCOC's MAB. PCOC's EDG is responsible for the management and oversight of the operational functions of PCOC on day-to-day management, financial reporting and other accountability requirements. This includes: ensuring the collection, analysis, reporting and development of PCOC data; the support to palliative care services to collect and use PCOC information; the review and approval of data requests; and the promotion of research and development opportunities with the data collected, and helping to marshal resources to deliver these opportunities.
23. PCOC's MAB and EDG, participating services and other committees and groups, including PCOC's Scientific Advisory and Clinical Advisory Groups, provide advice in order to improve PCOC's data policy. This may include, and is not limited to, matters regarding data collection, maintenance and security, reporting and access.
24. PCOC's Director (or another nominated by PCOC's Executive Director) maintains and updates PCOC's data policy.
25. PCOC staff are responsible for the administration and maintenance of the PCOC longitudinal database.

Data ownership

26. Services participating in PCOC are the original custodians of the data they supply to PCOC and retain ownership of the intellectual property relating to those data.
27. AHSRI is the custodian of the PCOC longitudinal database and owner of the intellectual property relating to the PCOC longitudinal database.
28. PCOC reserves the right to negotiate ownership of data once integrated and or to establish a formal agreement regarding use and ownership of data that is integrated with another dataset.

Requirements of services participating in PCOC

29. Services participating in PCOC sign a registration form where they agree to:
 - a) Allow the data they submit to be used for reporting, benchmarking and research purposes.
 - b) Ensure that the data they collect are complete, accurate and meet definitions outlined in the PCOC Data Dictionary and Technical Guidelines documents, which includes an outline of data items, their definitions and validation rules.
 - c) Take responsibility for ensuring that the data they submit to PCOC is collected in accordance with relevant Commonwealth, State or Territory or other jurisdiction

legislation (including privacy legislation) designed to protect the privacy of individuals. It is the responsibility of the services participating in PCOC to keep track of relevant legislation.

- d) Absolve PCOC of any responsibility in relation to the way that data are collected or stored by the service participating in PCOC.

Confidentiality and privacy

- 30. As custodian and manager of the PCOC longitudinal database, AHSRI protects the privacy and confidentiality of individuals (the patient or resident or another) and services participating in PCOC by adhering to the codes of practice stipulated by the University of Wollongong, the PCOC MAB and the University of Wollongong Human Research Ethics Committee (HREC) and relevant Acts of Parliament, including Australia's Privacy Act.
- 31. The PCOC longitudinal database does not contain patient details such as name and address. Potentially identifying items, such as patient date of birth and postcode, are submitted to PCOC by services participating in PCOC. These items are used to derive other variables (e.g. age). Such items are only reported to the service that provided the data. This is shared on request by the service or in support of quality processes.
- 32. Information identifying the results of a specific service will not be distributed to another party unless requested and formal, written consent is provided by that service.
- 33. Within PCOC, participating services are identified according to a unique provider code. This code is not distributed to another party unless it is agreed to in writing by the service participating in PCOC.

Ethical requirements

- 34. PCOC is responsible to the University of Wollongong HREC. PCOC has responsibility to comply with obligations under the Privacy Act and guidelines including the Australian Code for Responsible Conduct of Research and the National Statement on Ethical Conduct in Human Research. Australian state and territory health departments have signed a Memorandum of Understanding for mutual acceptance of ethical and scientific review of multi-centre human research projects undertaken in public health organisations. The University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee is jointly registered and certified (EC00150) with the National Health and Medical Research Council of Australia.
- 35. PCOC is required to:
 - a) Obtain ethical approval from the University of Wollongong Human Research Ethics Committee for the collection, maintenance, analysis, research and reporting of data from the services participating in PCOC; and provide annual reports to the University of Wollongong HREC for continuation.

- b) Obtain approval from the University of Wollongong HREC for any changes to PCOC protocols and data items which may affect the conduct of the data collection, analysis or reporting.
 - c) Ensure all appropriate ethical approvals have been sought and approved prior to any release of research data from the longitudinal database.
36. Researchers are required to obtain their own ethical approval to cover the conduct of their research.

Data items

37. The data items in the PCOC dataset have been chosen and defined in consultation with stakeholders.
38. The current data items are listed and described in PCOC's Data Dictionary and Technical Guideline documents.
39. Changes to data items are communicated to services participating in PCOC and documented in updated versions of the PCOC Data Dictionary and Technical Guidelines.

Data collection

40. All items in the PCOC dataset are collected and submitted by the services participating in PCOC.
41. Services participating in PCOC may enter data into their own software or software supplied by PCOC.
42. Services using their own software are required to:
- a) Liaise with the software developers to ensure the software is capable of collecting all data items in the PCOC dataset according to the PCOC protocol.
 - b) Ensure that the software can generate a PCOC data extract in the format required by PCOC, outlined in the PCOC Data Dictionary and Technical Guidelines.
 - c) Update their software when required. For example, following modifications to the PCOC dataset.

Data submission

43. Data is submitted electronically via a secure file upload facility hosted by the University of Wollongong.
44. Services participating in PCOC submit data to PCOC on a biannual basis (at a minimum) for the six month reporting periods ending June and December each year.
45. Services participating in PCOC submit records of all consecutively admitted patients (or residents), episodes and phases of palliative care during the reporting period.
46. Data received by PCOC are screened for missing values, errors and inconsistencies.

47. Data fields are not altered or adjusted by PCOC unless specifically requested / or agreed to by the service submitting the data.
48. Data quality reports are sent to services participating in PCOC for them to correct and resubmit the data.
49. Guidelines for the submission of PCOC data are provided to services participating in PCOC. These guidelines include detailed instructions regarding the file format required, the methodology for submitting data, and the error and quality checking processes for submitted data.

Data quality

50. PCOC develops and maintains guidelines and procedures to ensure the quality of the data and the meaningfulness of reports provided to services participating in PCOC. These include:
 - a) Providing data quality reports to services which detail errors, inconsistencies and missing data.
 - b) Providing clear timelines for data submission.
 - c) Maintaining and disseminating a PCOC Data Dictionary and Technical Guidelines document to reduce the variability in content and quality of the data obtained from each service participating in PCOC.
 - d) Ongoing support for and communication with services participating in PCOC.
51. The ability to provide quality and meaningful reports to services participating in PCOC is aided where palliative care services:
 - a) Undertake quality checks prior to the submission of data to PCOC to reduce the number of errors and missing variables.
 - b) Submit data according to the PCOC timelines.
 - c) Correct and resubmit data where PCOC's data validation process identifies errors or inconsistencies.

Data storage and security

52. All data received by PCOC are stored in electronic format.
53. Storage of the data is on a secure password-protected server located in a physically secure computer room at the University of Wollongong.
54. Access to PCOC data on the server is limited to staff involved in administration, management and analysis of PCOC data.
55. User accounts and IT infrastructure for PCOC are managed according to the University of Wollongong Information Technology Server Security Policy, ensuring appropriate levels of access, and password and username control (i.e. password strings, password ageing, password expiry dates).

56. PCOC stores working copies of data submissions on local desktop computers temporarily as required for analysis. These computers are password protected and have automatic screen locking.
57. Backup procedures for PCOC data are the responsibility of the University of Wollongong Information Management & Technology Services (IMTS). Backup requirements are documented and coordinated by IMTS according to the Minimum Server Security Standards outlined in the Information Technology Server Security Policy.
58. Disaster recovery procedures, including failover and redundancy are in accordance with the University of Wollongong policy for data security and the Information Technology Intrusion Response Plan outlined in the University of Wollongong Information Technology Server Security Policy.

Analysis and reporting

59. PCOC analyses the data provided by services participating in PCOC to routinely provide a number of different types of reports. These include:
 - a) Regular reports to individual services participating in PCOC containing:
 - i) Analysis of the service's data, with some data reported against the national data or a benchmark group.
 - ii) Achievement against benchmarks developed and agreed upon by the PCOC Management Advisory Board.
 - iii) Tables summarising data completeness).
 - b) A national PCOC bi-annual report describing the data submitted for a six-month period by all Australian services participating in PCOC. This includes demographic details of the population of people receiving palliative care services, outcomes for this group of patients as a result of treatment by services and service-related information.
 - c) Bi-annual reports describing the data submitted for a six-month period in Australian states (at a state level), where applicable, and elsewhere as identified by PCOC. These reports include similar information to that presented for services participating in PCOC, but reported at the state level. These reports do not identify the results of individual palliative care services and therefore are only provided in states large enough that individual services cannot reasonably be identified.
 - d) Bi-annual reports to specific consortia of services participating in PCOC. These reports identify specific services and are provided at the formal request of each of the services participating in PCOC who are part of the consortia.
 - e) Reports containing analysis of data collected through surveys.
 - f) Reports containing results from research studies and ad-hoc analysis.
60. PCOC staff may use information held in the PCOC longitudinal database to compile one-off reports to facilitate improvement in palliative care services, inform governance bodies

or for quality purposes. These reports may be presented at conferences or submitted for publication in journals. Results of individual services participating in PCOC will not be identifiable in any reports, publications or presentations, unless written permission has been sought from the participating service and received by PCOC from that service.

61. All reports contain aggregated data to ensure that the confidentiality of individuals and services participating in PCOC are maintained. PCOC ensures that results are not reported for small groups ($n < 5$) to avoid the inadvertent disclosure of information from which characteristics of an individual, service or a small distinctive population can be inferred. For example, where a jurisdiction has only a small number of services participating in PCOC, reporting at the jurisdictional level may identify individual services. In these instances one of the following occurs:
 - a) Data for the services may be combined with those of other jurisdictions to ensure confidentiality. Other (consequential) cells may also be suppressed to ensure data cannot be derived through deduction from the information available.
 - b) Following discussion and agreement with the PCOC Director (or another nominated by PCOC's Executive Director or Director), PCOC seeks formal agreement with the affected services participating in PCOC. The agreement highlights the fact that only a small number of services will be included.
62. PCOC reports include only valid data items, such that:
 - a) If data items are submitted with values in error and these are not corrected as part of the data validation process, these values are not included in reports.
 - b) Low data item completion may lead to values being excluded from reporting.

Data access

Scope of PCOC data available for requests

63. Data regarding patients, episodes and phases are provided to PCOC by services participating in PCOC throughout Australia. Each patient record contains demographic items. Episode records contain information about the patient's episode of care, and phase records and this includes assessment-level items. Additional items are collected periodically. The PCOC longitudinal database also contains a number of derived items.

Principles guiding the sharing and use of PCOC data

64. There are three purposes for which data from PCOC data may be shared:
 - a) *Quality improvement*: unit record data or aggregate data may be released to PCOC services to assist in their own quality improvement activities. Release of data for the purpose of quality improvement to a particular service will not include data which might enable identification of any other service, or patients from any other service.
 - b) *Research*: The use of the PCOC longitudinal database is encouraged for research whose objective is likely to strengthen the research evidence base for palliative care.
 - c) *Policy*: The use of PCOC data can be used to help influence and improve policy.

65. PCOC services who wish to use PCOC data for the purpose of quality improvement may contact the PCOC team directly. The PCOC team will advise regarding how to progress this request.
66. Researchers who wish to use PCOC data for the purpose of research must complete the form 'PCOC Application for Access and use of PCOC data for research purposes'.
67. Projects requesting extracts of data from the PCOC longitudinal database must meet appropriate standards of scientific merit and public health importance, as determined by the PCOC Executive Directors Group.
68. Applicants are required to make the results of their research using data from the PCOC longitudinal database publically available and accessible to the wider community. Proposed dissemination strategies are requested and listed on the 'PCOC Application for access and use of PCOC data for research purposes' form.
69. Only data items of a sufficiently high-quality are released. This is determined by a minimum of one of the PCOC Chief Investigators, in collaboration with the PCOC data and statistical staff, and the PCOC Director.
70. PCOC releases the least sensitive level and number of data items practicable to fulfil the requirements of the research proposal.
71. There are two categories of data which PCOC may release for use:
 - a) *Aggregated data* - manipulation of data by totalling the number of cases meeting specific criteria, or summing data items for specific subpopulations.
 - b) *Unit record data* - records that relate to an individual who has commenced an episode of care (according to the PCOC definition in the PCOC Data Dictionary and Technical Guidelines) with a service participating in PCOC. Before data sharing occurs, facility identifiers and patient variables that could potentially, or in combination with other variables, identify a patient are removed.
72. PCOC maintains a register of data access requests, which is tabled at the Management Advisory Board meetings.
73. PCOC reserves the right to dissociate itself from conclusions drawn from the data if it deems necessary.

Process for requesting aggregated data

74. Requests are made in writing using the 'PCOC Application for access and use of PCOC data for research purposes' form.
75. The application is initially reviewed by the PCOC Director, and forwarded to the Executive Directors Group for approval. The PCOC Director is a member of the Executive Directors Group.
76. Cell sizes of less than five are suppressed to avoid identification of an individual or service participating in PCOC. Other (consequential) cells may also be suppressed to ensure data cannot be derived through deduction from the information available.

Process for requesting unit record data

77. In exceptional cases, where provision of aggregated data is not sufficient to answer a research question, services participating in PCOC and stakeholders may request access to unit record data from the longitudinal database.
78. Unit record data will not be made available to for-profit, commercial entities.
79. Requests are made in writing using the PCOC 'Application for access and use of PCOC data for research purposes' form and submitted to the PCOC Director.
80. These requests are initially reviewed by the PCOC Director, and forwarded to the Executive Directors Group for review of scientific merit and potential to contribute to the research priorities (as determined by the PCOC Management Advisory Board.) The amount of resources necessary to fulfil the request, the source of the request, and intended use of the requested information is also taken into consideration in reviewing the application. On occasion, a fee-for-service may be requested to process the data access request and share the data.
81. Approved applications are prioritised for actioning by the PCOC Executive Directors Group.
82. Applications include evidence of compliance with relevant ethical requirements.

Data agreements

83. PCOC formally specifies any additional restrictions on the use of aggregated and unit record data where appropriate.
84. Data are only released on receipt of a User Agreement signed by all applicants in which they undertake to:
 - a) Use the information only for the purpose stated in their application.
 - b) Store the data in a secure manner and only for an agreed time period related to the purpose of the request¹.
 - c) Not provide the data to any person who is not named on the User Agreement.
85. Applicants provided with PCOC data may be requested to submit a progress report to PCOC every six months (or at another timeframe nominated by PCOC) for the life of the project. These reports will be reviewed by PCOC, and if necessary, referred to the PCOC's EDG. If progress reports are not completed or indicate limited progress, PCOC reserves the right to revoke approval for a project, and/or to decline access to PCOC data for further projects.

¹ User agreement point 6 and Data Policy Doc p1472b): In accordance with the Australian Code for the Responsible Conduct of Research (2007), data will be retained for an appropriate period following completion of the project. Data will be stored in a safe and secure storage environment for the designated minimum period, after which it will be securely destroyed (e.g. hard copies will be shredded into confidential waste, electronic copies will be irretrievably deleted). NHMRC, 2007. Australian Code for the Responsible Conduct of Research, Section 2 Management of Research Data and Primary Materials. Australian Government, Canberra.

This will help to ensure timely availability of the outcomes of research and the availability of PCOC data to those that may make full and optimal use of this valuable resource.

Data linkage

86. All data linkage projects are to be preceded by a discussion between the PCOC Director and PCOC data and statistical staff and representatives of the secondary dataset and or research team to be linked to the PCOC data (or research project leader), to confirm that data linkage is feasible based on the data held in the datasets to be linked.
87. Where data linkage is considered feasible, approval for linkage must be obtained by the researcher from all data custodians.
88. Projects involving the use of linked data also require a project-specific HREC approval. The project-specific HREC approval considers all issues related to the project, including the specific process used for that data linkage, any issues related to identifiability of the linked dataset and the risks and benefits of the project to people whose data will be used.
89. A data sharing arrangement is then to be established, indicating:
 - Which variables will be disclosed to facilitate data linkage (by whom and to whom)
 - Which variables will be included from each dataset in the linked research dataset
 - The scope of records to be included from each dataset (based on date range and/or patient characteristics)
 - Which party will conduct the probabilistic linkage
 - Which of the parties will hold the linked research dataset, or the process for disclosing each party's component of the linked research dataset to the research team
 - The conditions of use for the linked research dataset – i.e. will the linked research dataset be used in one research project only, or used initially in a research project and preserved for use in future projects
 - Any additional requirements identified by PCOC, and
 - Agreement on authorship of any resultant outputs.

Reporting and publication of released data

90. While PCOC expects that applicants make the results of their research accessible in the public domain, specific conditions apply to the reporting and publication of PCOC aggregated data released to users:

- a) To ensure that the data and any limitations in scope or quality of the data provided has been sufficiently understood by the user, pre-publication drafts of any derivative works are submitted to the PCOC Director for review and potential advice on data interpretation from the PCOC team.
 - b) PCOC is acknowledged as the source of the data.
 - c) Results are not to be presented in such a way that individuals and/or services participating in PCOC could be identified, unless written consent has been provided to PCOC by participating services.
 - d) PCOC reserves the right to negotiate with the applicant for co-authorship on any publication utilising PCOC data.
91. PCOC reserves the right to withdraw permission to publish the data as per the conditions of the User Agreement.

Data destruction and disposal

92. There are no provisions for the destruction or disposal of the data submitted by palliative care services to PCOC. PCOC is an ongoing collaboration with the palliative care sector with the aim to maintain the longitudinal database that is used to create sector-specific benchmarks and measure outcomes for patients receiving palliative care services. This longitudinal database has grown over time to provide a valuable resource for these purposes and for the wider scientific community to conduct research into palliative care.

Version control and change history

Version Control	Date Effective	Approved By	Amendment
1.0	1 November 2017	Executive Directors Group	-
2.0	07/11/2020	Executive Directors Groups	References, legislation and supporting documents update, inclusion of provision for data linkage, inclusion of additional principles, clarification between data release and data sharing, inclusion of option for fee-for-service, revised definition of aggregated data, inclusion of role of PCOC's Scientific and Clinical Advisory Groups

[end]