North West London
Whole Systems Integrated Care

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Privacy Impact Assessment Report

Version 2 , August 2015

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Project:	**WSIC**
Document owner(PM):	**Sonia Patel**
Document author:	**Debbie Terry**
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Client Contacts

Distributed to	Commented (version and date)
Selin Barnett	**1.1R.0 – 27.07.15**
David Stone	**1.1R.0 – 27.07.15**
Alistair Robertson	**1.1R.0 – 27.07.15**

Contents

1 Introduction

1.1 A Privacy Impact Assessment (PIA) is a systematic process that is used to analyse privacy law compliance within a system, which helps to identify, understand and manage or reduce the privacy risks whilst allowing the aims of the project to be met.

1.2 A PIA for the North West London Whole System Integrated Care project was completed in April 2015. One of the recommendations (15) was to review the PIA on a regular 3 monthly basis to ensure remedial actions are taken as recommended and the project keeps pace with legislative change and developing national guidance.

1.3 This document is the product of the first revision.

1.4 The revision was conducted in the period between the Health and Social Care (Safety and Quality) Act receiving Royal Assent and enactment. The Act introduces a legal duty to share information to support an individual's care when it is in their best interest to do so and when they have not objected. This puts the 7th Caldicott Principle – *the duty to share information can be as important as the duty to protect confidential information* – introduced by the Independent Information Governance Review (Caldicott2) onto a legal footing. It also introduces a duty to share information using the NHS number.

1.5 The implementation of the Act in October 2015 will be supported by operational guidance from the Department of Health. Whilst the principle of the Act is evident its application in some parts is not transparent, therefore the second revision of the PIA (November 2015) will be used to confirm, amend or add to the recommendations made in this version, which are based on reasonable assumptions.

1.6 The focus of the project is also changing. The first PIA supported the development of the system. This and subsequent reviews will start to guide the operational process for using the integrated care record.

2 Executive summary

2.1 A summary of the recommendations from PIA v1 legal review and commentary is available in Appendix A.

2.2 Much work has been completed on the recommendations from the first version of the PIA, however there are still some gaps predominantly in areas where there is a dependency on others and/or due to complexities of the task and competing priorities.

2.3 The implementation of the Health and Social Care (Safety and Quality) Act in October 2015 will be supported by operational guidance from the Department of Health. The second revision of the PIA (November 2015) will be used to confirm, amend or add to the Recommendations made in this version.

2.4 In addition, the Information Governance Alliance are on target to publish a series of information governance guidance, which will need to be considered in line with this PIA to ensure we continue to operate in accordance with national best practice standards.

2.5 The review has identified further areas in need of attention therefore some additional recommendations are made as follows:

PIA Version 1 (Revision) No:	Lawful basis	Page	Recommendation
R1.17	Data Protection Act - Fair processing	10	The communications strategy needs to be tested to ensure fair processing information is reaching the hard to reach groups.
R1.18	Data Protection Act - Fair processing	10	It is recommended that a review the layout of the website is conducted to ensure it is user friendly from a patient/public perspective. This is a slight adjustment to what is an extremely good well-presented website that is full of well-designed information to support both staff and the public.
R1.19	Data Protection Act - Fair processing To support Health and Social Care (Safety & Quality) Act 2015	11	The developing guidance should be reviewed to ensure that it includes reference to the new duty to share information unless the patient objects. The guidance should include what steps need to be taken in the event of a decision to object i.e. (a) how to record an objection and (b) the need to explain the consequence of the decision to the patient i.e. how it will impact on the quality of care.

R1.20	Common Law Duty of Confidence	12	Non-GP partners need to decide how they are going to achieve their part of the contract and provide a Patient Opt-out Management Service.
R1.21	Data Protection Act & common law	13	The Governing group should consider the option of initiating research into the risk stratification/information governance impasse in order to mitigate risk and move the project forwards.
R1.22	Data Protection Act	14	The process of purging records following a patient registering dissent should be tested to determine a realistic time between objection and removal from the system so patients' expectations can be appropriately managed and a performance measure established to monitor compliance.
R1.23	Data Protection Act & Human Rights	15	The Governing Group are advised to initiate a work stream to address the need to produce a comprehensive data sharing plan which provides detail of what clinical information needs to be seen on screen, who is authorised to see it and the need to see the data is justified.
R1.24	Governance	17	The specific NHS Records Management Standard (Part 2) for Audit Trails (Electronic Health Records) for WSIC audit data to be retained until further notices should be added to the ISA (section 8.2) for the avoidance of doubt
R1.25	Governance	17	The retrieval, usability and reliability of the audit data should be tested to ensure that it is fit for purpose to support medico-legal purposes and other disputes.
R1.26	Data Protection Act	19	Review all data processor

			contracts using the 32 point contract check list and present the completed check list to the Governing Board highlighting any gaps or concerns. The Governing Board to agree remedial action. Further assessment of this recommendation to be made in the next scheduled review of the PIA.
R1.27	Governance	19	The Governing Body is asked to note the value of these on-going reviews and approve the recommendation for the next review of the PIA in November 2015.

2.6 A list of all of the recommendations and status from both the first report and this revision is provided in Appendix B.

3 Omissions & Clarification PIA v1.1

3.1 The PIA summarises certain rights and duties relating to information sharing. It does not refer to the Caldicott duty to share information, recently made statutory by the Health and Social Care (Safety and Quality) Act 2015 (which has received Royal Assent but is not yet in force).

3.2 The Health and Social Care (Safety and Quality) Act 2015 is due to be enacted in October 2015. The Act introduces two new duties (in summary):

- To use a "consistent number" (the Secretary of State will make regulations to establish the NHS number as the consistent number); and
- To share information to "facilitate the provision of health or social care to the individual" when it is in their best interests and they have not objected.

3.3 There are definitions and exceptions embedded in the Act, some of which require regulations to be issued for clarity and all of which will be supported by implementation guidance issued by the Department of Health.

3.4 The duty to share applies to direct care purposes. It puts the 7th Caldicott Principle – *the duty to share information can be as important as the duty to protect confidential information* – introduced by the Independent Information Governance Review (Caldicott2) onto a legal footing.

3.5 The Data Protection Act 1998 and Common Law Duty of Confidence still apply, however, the purpose of the Act is to impose the presumption of sharing data to support direct care (breaking down the cultural barriers that previously impeded sharing) as long as the patient has not objected.

3.6 This emphasises the need for good informative fair processing communications to ensure the public are fully aware of the intention to share their personal data for specified direct care purposes and they know about their right to object and who to contact should they wish to exercise it.

3.7 This is reflected in the PIA revision by adding to existing recommendations or through the introduction of new recommendations.

3.8 The PIA states that it follows the Information Commissioner's Office "Conducting Privacy Impact Assessment Code of Practice.

3.9 The PIA follows and builds on the ICO's Code of Practice.
Overview of the PIA process (ICO CoP):

- Identify the need for a PIA;
- Describe the information flows;
- Identify the privacy and related risks;
- Identify and evaluate privacy solutions;
- Sign off and record the PIA outcomes;
- Integrate the PIA outcomes back into the project plan.

3.10 The ISA is legally binding only to the extent that it governs relations between data controllers and data processors. This is amended in section 22.2 of the ISA. Future iterations of the PIA should address this.

4 Update on the recommendations in PIA v1

4.1 PIA v1 Recommendation 1 – improve transparency

> *Improve transparency and openness by reviewing the "Resources" information on the WSIC website designed to inform patients about the uses of their personal data, to ensure it is free from codes and acronyms that an ordinary person would not reasonable be expected to understand. Seek advice from the Lay Partners Forum to test all publications are clear, relevant and understandable.*

4.1.1 The Communications Group has been active in reviewing resources, developing new materials, testing them with the lay partners and updating the website.

4.1.2 This includes the production of FAQs and on-line/downloadable information in easy read versions and for people whose first language is not English.

4.1.3 In addition, user guides have been developed for WSIC dashboard users, including a video to explain the purpose of the clinical dashboard, the legal basis for using patient identifiable data and a demonstration of how the system works. This work is commendable.

4.1.4 The WSIC data flow map, data templates and Exclusion codes documents however, still contain clinical codes, acronyms and technical language that the public would not be able to understand unless interpreted. The PIA recommendation to improve transparency by offering a glossary of terms or explanation/interpretation where things are not clear or would not be readily understood by a lay person has yet to be addressed.

4.1.5 In addition, whilst materials have been produced in easy read and different languages, it is important for the Project to make sure this information is reaching the hard to reach population. The significance of this has been raised by the introduction of the Health and Social Care (Safety and quality) Act 2015 because the duty to share information supported by the implied consent of the individual is indicated by the absence of an objection to satisfy the common law duty of confidentiality.

4.1.6 Part of this review involved a re-visit to the NWL WSIC website to evaluate the new materials. These proved a little difficult to find. The link to the "Resources" page which held the information for patients/the public has been moved from the "Home" page and now links from the "Informatics" page.

Integration.healthiernorthwestlondon.nhs.uk – Home

- Informatics
  - > Communications
  - > WSIC ISA Governing Group
  - > Useful links
  - > Information Sharing.

4.1.7 The first page of the "Informatics" section is designed for staff/user of the WSIC system.

4.1.8 The "Communications" section contains information to tell professionals and people using health and care services to understand what is planned. The "Information Sharing" section holds a set of documents to enable partner organisations to share to care data in North West London.

4.1.9 As the amount of information increases it is understandable that it is necessary to order it into layered sections for ease of use. However, the website is the first line of communication that the project relies on to inform the public and NWL staff and keep them updated. Therefore:

a) The patient information that supports all of the WSIC transparency and openness agenda and adds depth and clarity to the fair processing information should be of higher ranking in the order of priority; and
b) Information should be much more accessible to patients/the public and it should be obvious to them what information is held and where to find it (for example would it be obvious to them that they should follow the "Informatics" link; would they know that there is more useful information not held on the "communications" page etc.).

4.1.10 **Recommendation R1.17**
The communications strategy needs to be tested to ensure fair processing information is reaching the hard to reach groups.

4.1.11 **Recommendation R1.18**
It is recommended that a review the layout of the website is conducted to ensure it is user friendly from a patient/public perspective. This is a slight adjustment to what is an extremely good well-presented website that is full of well-designed information to support both staff and the public.

4.2 PIAv1 Recommendation 2 – develop a script for consent

> *A documented procedure and script should be developed to guide front-line staff in how to obtain explicit patient consent and record opt-out codes into the GP system to ensure individual patient choice is upheld. The script should include appropriate wording to (a) explain choices available to them and what questions to ask to obtain explicit consent; and (b) explain the impact to their direct care if a patient dissents, including appropriate action to be taken when an opt-out decision has to be overridden.*

4.2.1 The Communications Group is working in a "Patient Consent Management Strategy" which includes scripting guidance for staff in line with this recommendation.

4.2.2 One product under development is an IG booklet, which will include consent/opt-out options and GP Read Codes to record patient choices against their GP record.

4.2.3 It is important that this work is aligned with the imminent duty covered by the Health and Social Care (Safety and Quality) Act 2015 because the legal duty to share engages if the patient has not objected.

4.2.4 **Recommendation 2.19**
The developing guidance should be reviewed to ensure that it includes reference to the new duty to share information unless the patient objects. The guidance should include what steps need to be taken in the event of a decision to object i.e. (a) how to record an objection and (b) the need to explain the consequence of the decision to the patient i.e. how it will impact on the quality of care.

4.3 PIA v1 Recommendation 3 – develop a WSIC Consent Management Strategy

> *Develop a WSIC Patient Consent Management Strategy and provide practical guidance for GPs in how to approach patients and manage their respective choices. Supporting communication materials for patients must clearly explain their NHS Constitution rights to object to their personal data being used for in-direct care purposes*

4.3.1 Non-GP systems do not have the capability to record Read Code consent and objection codes, however, (and with particular reference to 3.2.4), partners need to give serious consideration to this requirement and work out a local procedure for managing and recording patient dissent. This is a contractual obligation as well as a legal one.

4.3.2 **Recommendation 2.20**

Non-GP partners need to decide how they are going to achieve their part of the contract and provide a Patient Opt-out Management Service.

4.4 PIA v1 Recommendation 4 – ensure future-state systems record consent

The WSIC Patient Consent Strategy should identify all consent and opt-out requirements and ensure future-state systems can support various levels of patient choice.

4.4.1 As previously stated, only GP systems have the technical capability to record consent and opt-out codes. Therefore, the WSIC system will have to rely on operational procedures to manage choice in non-GP Partner systems.

4.4.5 Full capability will be achieved in the longer term when "Patient Knows Best" is fully operational.

4.5 PIA v1 Recommendation 5 – reconsider the lawful basis for case-finding

The Governance Group should reconsider the lawful basis for processing patient confidential data for a "case finding purpose" as the reliance on implied consent does not appear to meet national or professional guidance. The outcome should inform the WSIC Patient Consent Strategy.

4.5.1 This recommendation was withdrawn following discussion and agreement that "case-finding" and "risk stratification" were different purposes and different lawful basis applied. However, there is still an unresolved issue about the lawful use of matching SUS data to GP data for these purposes.

4.5.1 NHS England have withdrawn their Risk Stratification & Information Governance Guidance and have not re-issued an updated version. This is (we believe) is because several information governance issues remain unresolved. Absence of clear national guidance means a heavy reliance on local interpretation, which carries a risk of uncertainty of which legal basis can be relied upon in absence of explicit consent.

4.5.2 There are two options for the WSIC project – either:
a) Proceed at risk whilst waiting for new national guidance is published; or
b) Commission a piece of research (e.g. via Imperial College Health Partners) to make recommendations to assist in the mitigation of local risks.

4.5.3 Option (b) gives the Governance Board more control over what otherwise is a stalemate situation. In addition to addressing local needs, the recommendations from the shared with the Information Governance Alliance can be used to support other Integrated Care pilots and will aid the speedier development of national guidance.

4.5.6 **Recommendation 2.21**

The Governing group should consider the option of initiating research into the risk stratification/information governance impasse in order to mitigate risk and move the project forwards.

4.6 PIA v1 Recommendation 6 – develop a communications plan

Develop a communications plan to support the GP Practice Data Controllers in their duties to ensure their registered patient population are adequately informed and have a reasonable period of time in which to register any objections before data is extracted for the WSIC system

This is happening – there are dependencies on recommendations 1, 2 &3.

4.7 PIA v1 Recommendation 7 – review the ISA section 8

The Governing Group should review the Information Sharing Agreement section 8 to either (a) permanently delete data held in the WSIC when a patient registers an objection, or (b) inform the patient of the intention to hold hidden data for a period of six months and allow them to raise a further objection if they do not they agree to that.

4.7.1 This recommendation refers to section 8.1 of the WSIC ISA.

4.7.2 The recommendation has been accepted and agreement to purge patient data from the system when their dissent is registered by their GP. The ISA will be updated accordingly.

4.7.3 A reasonable period of time needs to be allowed for the technical operation to be completed.

4.7.4 **Recommendation 2.21**

The process of purging records following a patient registering dissent should be tested to determine a realistic time between objection and removal from the system so patients' expectations can be appropriately managed and a performance measure established to monitor compliance.

4.8 PIA v1 Recommendation 8 –keep up to date with legal changes

The Governing Group are advised to be aware of the conditions for processing personal data and regularly review the WSIC data flows against changing circumstances to ensure there is a current and future legal basis to support the usage and proposed usage of data. It is also important to be aware of the requirement to inform patients about their right to object to secure any legal basis relied upon

4.8.1 Work is underway to re-map all data flows and confirm the lawful basis for processing.

4.8.2 There are outstanding issues with HSCIC that are slowing resolution. The HSCIC are not fully recognising a revision of the law that allows data flows, but work is in progress to resolve this issue.

4.9 PIA v1 Recommendation 9 – ensure data is relevant and proportionate

The clear purpose for the WSIC system should be determined, following which the data items in the Data Schedules should be reviewed to ensure they are relevant, proportional and necessary to meet that purpose. The RCP Guidance should be followed to determine the content of the Integrated Care Record.

4.9.1 The PIA records that the data sets contain "*a variety of administrative and clinical data, not all of which (the majority of which) could be justified as being necessary for a direct care purpose.*"

4.9.2 The PIA challenges what is the lawful basis for transferring this data into the warehouse, as it cannot be implied consent to sharing for direct care. The PIA questions whether this data is excessive, contrary to the third data protection principle, for the expressed purpose of providing direct care.

4.9.3 In addition to the production of guidance to support patient consent and objection management, a consent workshop is also being arranged for WSIC partners to develop operational procedures for extending the system to a new model of care.

4.9.4 Clinicians need to decide and justify what information they need to see on screen to determine clinical need.

4.9.5 Social care similarly need to state what information they need for their purposes and justify why they need to see it.

4.9.6 This requires clinical leadership to oversee the process, ensure the views of all clinical disciplines are covered and act as arbitrator over disagreements.

4.9.7 **Recommendation 2.23**

The Governing Group are advised to initiate a work stream to address the need to produce a comprehensive data sharing plan which provides detail of what clinical information needs to be seen on screen, who is authorised to see it and the need to see the data is justified.

4.10 PIAv1 Recommendation 10 – arrangements for managing inaccuracies

A whole systems procedure for managing inaccuracies in the Integrated Care Record focussed around a central point of contact to support front line staff in the reporting and correction of data should be established. The procedure should be documented to identify responsibilities and provide clear instruction to staff to ensure a consistent approach.

4.10.1 Data pooled from different systems may hold discrepancies that front-line staff may not be able to manage as the correction needs to flow from the source systems in a logical order so accurate data is not overwritten by inaccurate data. A central point of contact to coordinate the correction of data inaccuracies was proposed.

4.10.2 Further work needs to be done to design the system for managing corrections. A proposal is to include a free-text messaging system so staff can communicate with each other to query which version is correct and request changes. However, this is one suggestion of probably many options to establish a workable and reliable procedure.

4.10.3 It emphasises the need to consider and agree the operational process for using a shared care record.

4.10.4 Progress on this recommendation will be assessed in the next scheduled PIA review.

4.11 PIAv1 Recommendation 11 – real time entry of clinical information

> *The system specification should include future-state capability to ensure a full digital integrated care record that supports real time entry of clinical information.*

It is agreed that this recommendation is aspirational and for future consideration. It is therefore closed for the moment.

4.12 PIAv1 Recommendation 12 – medico-legal assurance

> *Data should be retained in accordance with the NHS Records Management Code of Practice in a format that enables it to be reproduced in accordance with recognised medico-legal standards for the lifetime of that record. Assurances that this requirement will be included in future state systems is essential and therefore must be included in system specifications.*

4.12.1 The system is a view only system supported by an audit trail. The audit data is retained in accordance with the NHS Records Management Standard. This is confirmed in the ISA (8.2).

4.12.2 The retention period should comply with the NHS Records Management Standard (Part 2) – Audit Trails (Electronic Health Records) which specifies that all data should be retained until further notice. This should not be confused with the Audit records – "system audits" standard which states the data should be retained for 2 years.

4.12.3 **Recommendation 2.24**

The specific NHS Records Management Standard (Part 2) for Audit Trails (Electronic Health Records) for WSIC audit data to be retained until further notices should be added to the ISA (section 8.2) for the avoidance of doubt.

4.12.4 Audit trails are important for medico-legal purposes as they enable the reconstruction of records at a point in time. Without its associated audit trail, there is no reliable way of confirming that an entry is a true record of an event or intervention.

4.12.5 It is uncertain how this data would support a query or dispute e.g. in a WSIC medico/legal hearing.

4.12.6 **Recommendation 2.25**

The retrieval, usability and reliability of the audit data should be tested to ensure that it is fit for purpose to support medico-legal purposes and other disputes.

4.13 PIAv1 Recommendation 13 – management of subject access requests

The Governing Group are advised to review the Information Sharing Agreement section 6.5 decision on arrangements for dealing with subject access requests. The Integrated Care Record held in the WSIC system is an accessible record and patients have a legal right to be provided with a copy upon request.

4.13.1 Each Provider Partner, as a data controller, is responsible for dealing with SARs that it receives. There is also an obligation on each Partner to assist the others in responding to any such request.

4.13.2 The PIA challenged the arrangements in the ISA for dealing with subject access requests – "*Current arrangements are to refer an individual requesting access to their records back to the source provider of their personal data… It would be unlawful to refuse to provide an individual patient with a copy of their WS integrated care record and the ISA needs to be updated to include a central point for dealing with SARs.*"

4.13.3 The concern was that patients may have to make a series of SARs – one to each organisation holding their personal health data in order to obtain all of the information pooled in the WSIC system. This is onerous, potentially expensive if each data controller charges for the service (as they are legally entitled to so so) and risked a challenge of unfairness.

4.13.4 In addition, the right of access is not absolute and disclosure of health records in response to a SAR has to be considered to determine whether or not to apply the "harm" exemption i.e. disclosure could cause harm to the data subject or any other person, which, for health data can only be decided by an "appropriate health professional". The harm exemption also applies to social care data and an exemption to the disclosure of third party data applies to both health and social care data. This s required by law[1].

4.13.5 The ISA has been updated and now reads (new section highlighted):

S6.5 As each Provider Partner is a Data Controller in its own right, each shall be responsible for handling any subject access request made under s. 7 of the Data Protection Act. Additionally each Partner shall assist the others in responding to any such request or other request made under Data Protection Legislation made by persons who wish to access copies of information held about them, in accordance with clause 13 of the Information Sharing Protocol. The Provider Partners agree that if a patient submits a subject access request for information held in the patient's Individual Integrated Care Record, that patient should not have to pay more than one fee in order to receive the information to which the patient is entitled.
The Provider Partners also agree that any disclosure in response to a subject access request should be authorised in advance by a person who is professionally capable of determining that disclosure would not cause serious harm to the requester or to another person's physical or mental health or condition".

4.13.6 This recommendation is now complete.

4.14 PIAv1 Recommendation 14 – review data controller/data processor contracts

The Governing Group should review the existing data controller/data processor contracts to ensure they (a) clearly identify those data controllers the contract applies to and (b) clearly include the DPA seventh principle conditions for information security. The contracts should be subsequently reviewed on an annual basis (or earlier if circumstances dictate)

[1] The Data Protection (Subject Access Modification) (Health) Order 2000 SI 2000 No.413. The Data Protection (Subject Access Modification)(Social Work) Order 2000 SI No.415

4.14.1 A thorough contract revision underway using 32 point contract checklist.

4.14.2 The Governing Body will be presented with the completed check list for each data processor contract with any identified gaps or concerns highlighted.

4.14.3 This will also be assessed in the next scheduled PIA review.

4.14.4 **Recommendation 2.26**

Review all data processor contracts using the 32 point contract check list and present the completed check list to the Governing Board highlighting any gaps or concerns. The Governing Board to agree remedial action. Further assessment of this recommendation to be made in the next scheduled review of the PIA.

4.15 PIA v1 Recommendation 15 – review the PIA on a regular basis

This PIA is a progressive living document and should be reviewed on a regular basis by the Governing Group on a regular basis (every 3 months initially moving towards an annual review when stable) to ensure remedial actions are taken as recommended and the outcomes and risks are considered in line with legal changes and developing guidance.

4.15.1 This completes the first review of the PIA.

4.15.2 In addition to the aforementioned enactment of the Health and Social Care (Safety and Quality) Act 2015 in October 2015, the Information Governance Alliance is on track to publish a series of information governance guidance in response to the Integrated Care “deep dive” and other demands for clarity on a wide variety of subjects.

4.15.3 **Recommendation 2.27**

The Governing Body is asked to note the value of these on-going reviews and approve the recommendation for the next review of the PIA in November 2015.

4.16 PIA v1 Recommendation 16 - SIRO

The Governing Group should take ownership of the risks and issues and ensure through regular review that those risks are mitigated through the implementation of the recommendations from the PIA. A SIRO should be appointed and take responsibility for holding the risk owners to account.

4.16.1 Aumran Tahir is the Senior Information Risk Owner for the Governing Group.

5 Appendix A PIA legal review and revision commentary

DAC Beachcroft

WSIC: Privacy Impact Assessment Report version1.0 dated 19 March 2015: legal review and revision commentary

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
1.1	The PIA summarises certain rights and duties relating to information sharing. It does not refer to the Caldicott duty to share information, recently made statutory by the Health and Social Care (Safety and Quality) Act 2015 (which has received Royal Assent but is not yet in force).	It may be helpful to refer to this duty here.	Health and Social Care (Safety and Quality) Act 2015 comes into force 1st October 2015 – duty to share added to the revised PIA	Complete
1.2	The PIA states that it follows the ICO's "Conducting Privacy Impact Assessment Code of Practice	I have not checked this	Confirm that it does follow the ICO Code of Practice and builds on it – PIA stages added to the revised PIA.	Complete

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
2.3	The PIA refers to the ISA being 'legally binding'.	NB that if proposed changes are agreed, the ISA will be legally binding only to the extent that it governs relations between data controllers and data processors. Future iterations of the PIA should address this.	ISA updated accordingly Relevant clause 22.1	Complete
Recommendation 1, para 3.3 and Appendix 3: CLDC / First principle	*Improve transparency and openness by reviewing the "Resources" information on the WSIC website designed to inform patients about the uses of their personal data, to ensure it is free from codes and acronyms that an ordinary person would not reasonable be expected to understand. Seek advice from the Lay Partners Forum to test all publications are clear, relevant and understandable.*	This is a good suggestion.	Recommendation added to the project plan. Subsequent work includes review of resources and testing with lay partners. Need to ensure accessible information guides are reaching "hard to reach" members of the public. Author reviewed Resources to include further comment in this revision.	On-going
Recommendation 2, para 3.3 and Appendix 3: CLDC / First principle	*A documented procedure and script should be developed to guide front-line staff in how to obtain explicit patient consent and record opt-out codes into the GP system to ensure*	This is a good suggestion.	Script under development by the communications group. Includes patient objection management	On-going

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
	individual patient choice is upheld. The script should include appropriate wording to (a) explain choices available to them and what questions to ask to obtain explicit consent; and (b) explain the impact to their direct care if a patient dissents, including appropriate action to be taken when an opt-out decision has to be overridden.		(Recommendation 3)	
Recommendation 3, para 3.3 and Appendix 3: CLDC / First principle	*Develop a WSIC Patient Consent Management Strategy and provide practical guidance for GPs in how to approach patients and manage their respective choices. Supporting communication materials for patients must clearly explain their NHS Constitution rights to object to their personal data being used for in-direct care purposes*	This is a good suggestion.	Non-GP partners need to state how they are going to achieve this to meet their contractual obligations. All included in the PIA Revision	On-going
Recommendation 4	*The WSIC Patient Consent Strategy should identify all*	This may need to be tempered by the practical abilities of the	Covered in recommendation 2&3.	Closed

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
	consent and opt-out requirements and ensure future-state systems can support various levels of patient choice.	system adopted.	Development of operational procedures in progress. Not there yet with technical capability - Patient Knows Best	
Recommendation 5 and Appendix 3: CLDC	*The Governance Group should reconsider the lawful basis for processing patient confidential data for a "case finding purpose" as the reliance on implied consent does not appear to meet national or professional guidance. The outcome should inform the WSIC Patient Consent Strategy.*	The PIA assumes that 'case finding' is equivalent to risk stratification. In my view there are three key differences: (1) information for case finding is available only to healthcare providers, not commissioners. The guidance cited in the PIA (e.g. the January 2015 NHSE guidance) highlights risks relating to risk stratification <u>by commissioners</u>. (2) providers will only be able to see case finding information about patients who they system identifies as being able to benefit	NWL Workshop arranged for 24th September 2015. NHSE Risk stratification guidance withdrawn and has not been re-issued. Absence of clear national guidance means reliance on local interpretation with risk/uncertainty of legal basis in absence of explicit consent. Further work to be work to be done – proposal for a coordinated piece of research underway.	On-going

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
		from a programme of targeted care. They will not be able to see information about patients who would not benefit. (3) the lawful basis for the sharing and linkage of patient information is implied consent to direct care, through the provision of the Integrated Care Record. Information is not being shared and linked for the sole purpose of case finding. On those bases, I would argue that the case finding purpose is legitimate.		
Recommendation 6	*Develop a communications plan to support the GP Practice Data Controllers in their duties to ensure their registered patient population*	This is a good suggestion, to the extent not already implemented.	This is happening – dependencies on recommendations 1, 2 &3.	On-going

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
	are adequately informed and have a reasonable period of time in which to register any objections before data is extracted for the WSIC system.			
Recommendation 7	*The Governing Group should review the Information Sharing Agreement section 8 to either (a) permanently delete data held in the WSIC when a patient registers an objection, or (b) inform the patient of the intention to hold hidden data for a period of six months and allow them to raise a further objection if they do not they agree to that.*	I had understood that deleting information immediately was technologically not possible. In which case, option (b) should be adopted.	ISA updated – information purged. Realistic time between objection and removal to be tested to inform patients and establish a performance measure.	On-going
Recommendation 8 and Appendix 3: DPA / "Lawful"	*The Governing Group are advised to be aware of the conditions for processing personal data and regularly review the WSIC data flows against changing circumstances to ensure there is a current and future legal basis to support the usage and proposed usage of data. It is*	I agree that the data templates and justification for flowing data should be reviewed regularly. The PIA suggests that GP system data, and SUS data, cannot be shared on the basis of implied consent for direct care. I assume this is because this data is not required for direct care, but I found this section of the PIA	Work underway to re-map data flows and lawfulness. Issues with HSCIC slowing resolution.	On-going

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
	also important to be aware of the requirement to inform patients about their right to object to secure any legal basis relied upon.	difficult to follow. I would recommend that the Governing Group approves further work in this area to determine whether there is an issue with the lawful basis for sharing certain data sets.		
Recommendation 9, para 3.2 and Appendix 3: DPA / Third principle	The PIA records that the data sets contain "*a variety of administrative and clinical data, not all of which (the majority of which) could be justified as being necessary for a direct care purpose.*" The PIA challenges what is the lawful basis for transferring this data into the warehouse, as it cannot be implied consent to sharing for direct care. The PIA questions whether this data is excessive, contrary to the third data protection principle, for the expressed purpose of providing direct care.	This is a powerful challenge. The ISA relies on implied consent to sharing for direct care, for the lawfulness of transferring data from provider source systems into the data warehouse. If data is transferred that is not intended to be used for direct care, implied consent to sharing cannot be relied upon. There is an argument that data that isn't needed at all, and that is purged on landing, can be said not to breach confidence, as no human sees that data. It is a further stretch (in my view too	Proportionality challenge – as system extends to a model of care it is essential to agree and justify what information should be available to see on screen to determine clinical need. This has to be done by front line health and social care professionals with a wide representation of clinicians to cover various specialties and clinical leadership to approve end results. Social care need to justify why they need to see as much as a clinician.	On-going

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
		far) to say that there is no breach of confidentiality if the data is immediately de-identified for use for commissioning purposes. I think that would be considered to be a breach of confidentiality.		
Recommendation 10, Appendix 3: DPA / Fourth principle	*A whole systems procedure for managing inaccuracies in the Integrated Care Record focussed around a central point of contact to support front line staff in the reporting and correction of data should be established. The procedure should be documented to identify responsibilities and provide clear instruction to staff to ensure a consistent approach.*	This is a good suggestion.	Operational procedures still in development. Front-line staff cannot change the system. Need to consider how you are going to manage discrepancies – the operational process for managing the shared record. Possibly add a free text messaging function for staff to communicate – check facts, request changes etc?	On-going
Recommendation 11	*The system specification should include future-state capability to ensure a full digital integrated care record that supports real time entry of clinical information.*	If achievable, this would be ideal. However, technological constraints may apply.	Agreed as an ambition.	Closed

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
Recommendation 12	*Data should be retained in accordance with the NHS Records Management Code of Practice in a format that enables it to be reproduced in accordance with recognised medico-legal standards for the lifetime of that record. Assurances that this requirement will be included in future state systems is essential and therefore must be included in system specifications.*	This is a good suggestion	View only record supported by audit trail – the audit data retained in accordance with the NHS record management standard. Uncertain how this data would support a query or dispute e.g. medico/legal hearing. Recommendation to test retrieval, usability and reliability of audit data added to revised PIA	On-going
Recommendation 13, para 3.1 and Appendix 3: DPA / Sixth principle	The PIA challenges the arrangements in the ISA for dealing with subject access requests. It states that "*Current arrangements are to refer an individual requesting access to their records back to the source provider of their personal data… It would be unlawful to refuse to provide an individual patient with a copy of their WS integrated care record and the ISA needs*	I don't think the ISA is inconsistent with the obligations referenced in the PIA. Clause 6.5 of the ISA provides that: *As each Provider Partner is a Data Controller in its own right, each shall be responsible for handling any subject access request made under s. 7 of the Data Protection Act. Additionally each Partner shall assist the others in responding to any such request or other request made under Data*	ISA Changed. Recommendation resolved.	Complete

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
	to be updated to include a central point for dealing with SARs"	*Protection Legislation made by persons who wish to access copies of information held about them, in accordance with clause 13 of the Information Sharing Protocol.* It must be right that each Provider Partner, as a data controller, is responsible for dealing with SARs that it receives. There is also an obligation on each Partner to assist the others in responding to any such request. If one Provider Partner receives an SAR for a patient's Integrated Care Record, it should decide whether it is obliged to provide that information under the DPA. The data controller may use the ISA to call on the others to assist it in providing that patient with his Integrated Care Record. The Governing Group may wish to consider whether the data controllers would like to appoint a person / organisation to be a central point of contact and		

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
		administrator of SARs for patients' integrated care records.		
Recommendation 14, Appendix 3: DPA / Seventh principle	*The Governing Group should review the existing data controller/data processor contracts to ensure they (a) clearly identify those data controllers the contract applies to and (b) clearly include the DPA seventh principle conditions for information security. The contracts should be subsequently reviewed on an annual basis (or earlier if circumstances dictate)*	This is a good suggestion. The PIA comments that it is not '*evidently clear*' from the ISA that the data processor (Brent) must comply with obligations equivalent to those imposed on a data controller by the seventh principle. I would like to understand what further obligations on Brent the PIA author would like to see. It may be an express obligation to comply with IGT level 2. If so, I would expect that this can be added for Brent, although it may be more difficult to impose on subcontractors, who may use different IG measures.	Contract revision underway – using 32 point contract checklist. Governing body to be presented with completed check list for each data processor contract completed with any gaps or concerns highlighted.	On-going
Recommendation 15	*This PIA is a progressive living document and should be reviewed on a regular basis by the Governing Group on a regular basis (every 3 months*	This is a good suggestion.	PIA Revision completed July 2015. Next revision proposed for November 2015.	On-going

Section / recommendation	PIA comment	DAC Beachcroft Response	PIA Revision 26th July 2015	Status
	initially moving towards an annual review when stable) to ensure remedial actions are taken as recommended and the outcomes and risks are considered in line with legal changes and developing guidance.			

6 Appendix B PIA Recommendations and status

Ref No.	Recommendation	Commentary	Status at 29/07/15
1.1	Improve transparency and openness by reviewing the "Resources" information on the WSIC website designed to inform patients about the uses of their personal data, to ensure it is free from codes and acronyms that an ordinary person would not reasonable be expected to understand. Seek advice from the Lay Partners Forum to test all publications	New resources developed and published. Lay Partners Forum reviewing Review identified 2 new recommendations regarding Testing to ensure communication materials reach hard to reach population (Ref R1.17) and Review accessibility of information on the	On-going

	are clear, relevant and understandable.	website (R1.18)	
1.2	A documented procedure and script should be developed to guide front-line staff in how to obtain explicit patient consent and record opt-out codes into the GP system to ensure individual patient choice is upheld. The script should include appropriate wording to (a) explain choices available to them and what questions to ask to obtain explicit consent; and (b) explain the impact to their direct care if a patient dissents, including appropriate action to be taken when an opt-out decision has to be overridden.	Work progressing under the Patient Consent Management Strategy Review identified new recommendation – review in line with incoming Health & Social Care (Safety & Quality Act) 2015 enactment October 2015. Ref R1.19	On-going
1.3	Develop a WSIC Patient Consent Management Strategy and provide practical guidance for GPs in how to approach patients and manage their respective choices. Supporting communication materials for patients must clearly explain their NHS Constitution rights to object to their personal data being used for in-direct care purposes	Patient Consent Management Strategy in development. New recommendation identified for Non-GP partners to decide how they are going to achieve their part of the contract and provide a Patient Opt-out Management Service. Ref R1.20	On-going
1.4	The WSIC Patient Consent Strategy should identify all consent and opt-out requirements and ensure future-state systems can support various levels of patient choice.	Full capability will be achieved in the longer term when "Patient Knows Best" is fully operational	On-going

1.5	The Governance Group should reconsider the lawful basis for processing patient confidential data for a "case finding purpose" as the reliance on implied consent does not appear to meet national or professional guidance. The outcome should inform the WSIC Patient Consent Strategy.	Unresolved issues with data flows from HSCIC – national view undecided. New recommendation to consider initiating research to aid the progress towards a solution. Ref R1.21	On-going
1.6	Develop a communications plan to support the GP Practice Data Controllers in their duties to ensure their registered patient population are adequately informed and have a reasonable period of time in which to register any objections before data is extracted for the WSIC system.	In progress – dependencies on recommendations 1, 2 & 3	On-going
1.7	The Governing Group should review the Information Sharing Agreement section 8 to either (a) permanently delete data held in the WSIC when a patient registers an objection, or (b) inform the patient of the intention to hold hidden data for a period of six months and allow them to raise a further objection if they do not they agree to that.	Agreement to purge data when patient registers an objection. New recommendation following revision to test the time it takes between opt-out request and actual purge from the system Ref R1.22	On-going
1.8	The Governing Group are advised to be aware of the conditions for processing personal data and regularly review the WSIC data flows against changing circumstances to ensure there is a	Work to re-map data flows and confirm legal basis in progress.	On-going

	current and future legal basis to support the usage and proposed usage of data. It is also important to be aware of the requirement to inform patients about their right to object to secure any legal basis relied upon		
1.9	The clear purpose for the WSIC system should be determined, following which the data items in the Data Schedules should be reviewed to ensure they are relevant, proportional and necessary to meet that purpose. The RCP Guidance should be followed to determine the content of the Integrated Care Record.	Not started. Need to move towards working out operational process for using the shared record. New recommendation to agree what data should be seen on screen. Ref R1.23	Not started
1.10	A whole systems procedure for managing inaccuracies in the Integrated Care Record focussed around a central point of contact to support front line staff in the reporting and correction of data should be established. The procedure should be documented to identify responsibilities and provide clear instruction to staff to ensure a consistent approach.	Not started. Front-line staff cannot change patient data. Re-visit at next review Nov 2015	Not started
1.11	The system specification should include future-state capability to ensure a full digital integrated care record that supports real time entry of clinical information**.**	Not there yet – aspiration/future consideration for system development	Closed
1.12	Data should be retained in accordance	Agreed	

	with the NHS Records Management Code of Practice in a format that enables it to be reproduced in accordance with recognised medico-legal standards for the lifetime of that record. Assurances that this requirement will be included in future state systems is essential and therefore must be included in system specifications.	Review identified 2 new recommendations Add specific RM Standard to ISA Ref.R1.24; and Test usability of audit data Ref. R1.25	On-going
1.13	The Governing Group are advised to review the Information Sharing Agreement section 6.5 decision on arrangements for dealing with subject access requests. The Integrated Care Record held in the WSIC system is an accessible record and patients have a legal right to be provided with a copy upon request.	Completed – ISA updated	Closed
1.14	The Governing Group should review the existing data controller/data processor contracts to ensure they (a) clearly identify those data controllers the contract applies to and (b) clearly include the DPA seventh principle conditions for information security and 9c) are visible. The contracts should be subsequently reviewed on an annual basis (or earlier if	In progress – all data controller/data processor contracts reviewed using 32 point contract checklist. Results/gaps/risks/concerns to be presented to the Governing Board. New recommendation ref. R1.26	On-going

	circumstances dictate)		
1.15	This PIA is a progressive living document and should be reviewed on a regular basis by the Governing Group on a regular basis (every 3 months initially moving towards an annual review when stable) to ensure remedial actions are taken as recommended and the outcomes and risks are considered in line with legal changes and developing guidance	1st review complete 2md review due November 2015	On-going
1.16	The Governing Group should take ownership of the risks and issues and ensure through regular review that those risks are mitigated through the implementation of the recommendations from the PIA. A SIRO should be appointed and take responsibility for holding the risk owners to account.	Aumran Tahir is the Senior Risk Owner for the Governing Group	Closed
Recommendations added at 1st revision of the PIA July 2015			
R1.17	The communications strategy needs to be tested to ensure fair processing information is reaching the hard to reach groups		
R1.17	It is recommended that a review the layout of the website is conducted to ensure it is user friendly from a patient/public perspective. This is a slight adjustment to what is an		

	extremely good well-presented website that is full of well-designed information to support both staff and the public.		
R1.18	The developing guidance should be reviewed to ensure that it includes reference to the new duty to share information unless the patient objects. The guidance should include what steps need to be taken in the event of a decision to object i.e. (a) how to record an objection and (b) the need to explain the consequence of the decision to the patient i.e. how it will impact on the quality of care.		
R1.19	Non-GP partners need to decide how they are going to achieve their part of the contract and provide a Patient Opt-out Management Service.		
R1.20	The Governing group should consider the option of initiating research into the risk stratification/information governance impasse in order to mitigate risk and move the project forwards.		
R1.21	The process of purging records following a patient registering dissent should be tested to determine a realistic time between objection and removal from the system so patients' expectations can be appropriately managed and a		

	performance measure established to monitor compliance.		
R1.22	The Governing Group are advised to initiate a work stream to address the need to produce a comprehensive data sharing plan which provides detail of what clinical information needs to be seen on screen, who is authorised to see it and the need to see the data is justified.		
R1.23	The specific NHS Records Management Standard (Part 2) for Audit Trails (Electronic Health Records) for WSIC audit data to be retained until further notices should be added to the ISA (section 8.2) for the avoidance of doubt		
R1.24	The retrieval, usability and reliability of the audit data should be tested to ensure that it is fit for purpose to support medico-legal purposes and other disputes.		
R1.25	Review all data processor contracts using the 32 point contract check list and present the completed check list to the Governing Board highlighting any gaps or concerns. The Governing Board to agree remedial action. Further assessment of this recommendation to be made in the next scheduled review of the PIA.		
R1.26	The Governing Body is asked to note the		

	value of these on-going reviews and approve the recommendation for the next review of the PIA in November 2015.		