Department of Health - Informatics Support Visit Report

Wednesday 8th and Thursday 9th January 2014

WORK IN PROGRESS: DRAFT

Executive Summary

Integrated Care Pioneers are a ministerial priority, they aim to enable and drive change throughout the whole health and social care system. An issue has arisen which suggests that information governance is hampering rapid advancement by the Pioneer sites. In addition to the support NHS IQ is offering, Norman Lamb has asked for a team of experts to work with one Pioneer site [Southend on-Sea] to resolve issues and produce ministerial advice on how a solution could be achieved.

The DH Team and the Southend Integrated Care Pioneer [SICP] team undertook an intensive and productive face to face exploratory and evaluative dialogue over 1.5 days to produce this report. The contents were completely open and transparent to all participants.

SICP are correct in their assertion that there is not a legal basis for the data flows they were using and wish to use in the future.

SICP and the DH team have an almost complete specification of what is needed and how it is envisaged to work specified within this report, including steps SICP needs to undertake to improve its own information governance.

The DH team with strong SICP scrutiny and input have proposed a short and long term solution, which requires senior officer support. The extent to which both are extensible and generalizable to the other Pioneer sites remains to be tested in a workshop with or without further visits to other sites. The long term solution will require a new regulation under the section 251 of the NHS Act 2006.

The findings from this study also bring the need for further policy clarification in a small number of issues relating to the nature of controlled environments and accredited safe havens, the degree of local versus national data collection, and the criteria applied to objection considerations, which have further impacts on the role of the Health and Social Care Information Centre and the potential rises in burden and bureaucracy from local collections.

This study strongly suggests that information governance should not be an impediment to the advancement of integrated care pioneers if the proposals put forward are accepted. Two potential groups of issues may have an impact of the rapidity of advancement these are policy issues and the degree to which local information governance practice needs to improve to meet the standards expected.

Context

Integrated Care Pioneers are a ministerial priority, they aim to enable and drive change throughout the whole health and social care system. An issue has arisen which suggests that information governance is hampering rapid advancement by the Pioneer sites. In addition to the support NHS IQ is offering, Norman Lamb has asked for a team of experts to work with one Pioneer site to resolve issues and produce ministerial advice on how a solution could be achieved. This will be followed by a workshop including all 14 pioneer sites to share and disseminate findings and practice, as well as ascertain whether any significant issues remain outstanding and hence require a second site visit. The minister is fully involved and keen for this work to be completed early in the New Year, with a workshop for all Pioneers in either late January or early February

The Pioneer site visited was Southend on-Sea and involved representatives from Southend on-Sea Borough Council, Southend CCG, NHS Central Eastern CSU and PI Benchmark

Objectives

1. Describe in detail the issues, which are hampering rapid development of integrated care and highlight where and how information governance is a or the causative factor
2. Confirm or refute information governance as a causative factor
3. Where information governance is confirmed as a causative factor agree an issue resolution plan for immediate implementation OR
4. Formulate advice to the minister by which resolution can be achieved through governmental action
5. Where IG as a causative factor is refuted the visitors should signpost to a person or service to resolve the issue.

Working Practice

- The work took place under Chatham House rule so that full exposure of the issues could take place
- Inception; the owners of the issues are the local team, these were captured with a one to two sentence high level description and a one to two sentence quantification of why it is important to solve this issue.
- Elaboration of the problem space for all issues took place, this was through local description and expert team seeking clarification and explanation through a round table discussion
- Design of a solution or plan for getting a solution was undertaken by the Department of Health Team and then tested with local team to assure not only systemic desirability but practical feasibility
- Implementation will take place through the local team for refuted items or agreed resolution plans. Implementation will take place through the DH visiting team for issues which require governmental action
- Reporting of the outputs to support the objectives was undertaken by the DH visiting team and shared with all participants.

- If in an unlikely scenario there are any issues where there are unresolved fundamental differences of opinion a resolution plan using a trusted third party will be set.
- Specific local IT system issues are outside scope but general issues of standards etc are in scope

Timetable and Participants

These are set out in Appendix 1.

Exclusions

1. A general assessment of the proposal in general or information governance in particular was excluded
2. The report only focuses on the perceived information governance issues from the Pioneer site and nothing more.
3. Direct care other than that stimulated via risk management case finding is not highlighted because there are no information governance issues deemed to exist in this space and practice with regard to this domain is viewed as advanced. The site will be providing a one page brief on that situation particularly their award winning SPOR service. This is set out in Appendix 2

Inception

There was only one issue identified that was causing concern and that issue was risk stratification.[1]

The Southend on-Sea Integrated Care Pioneer site agreed with the common description of risk management as set out in the footnote.

The Southend on-Sea Integrated Care Pioneer site felt it was crucially important to be able to undertake risk management [all types] because it was an essential aspect of better commissioning to[2]:

- Identify high cost individuals whose care may need to be reviewed by the multidisciplinary team with whom they have a legitimate relationship
- Map the density of one or more pathologies, impairments, functions, services and events within services across their locality for example by [political] ward
- Identify those with abnormal or perceived abnormal outcomes for example emergency admissions for alternative interventions
- Commission new services in an affordable manner by identifying populations of clients with certain constellations of features
- Assess whether new services are having the desired effects
- Feed into the Joint Strategic Needs Assessment
- Provide health and wellbeing boards with the data they require
- Support service planning
- Produce emergency plans
- Underpin the locality strategic plan
- Enabling analysts to investigate the data and come up with new commissioning innovations

[1] Risk stratification tools can help determine which people in a population are at high risk of experiencing outcomes, such as unplanned hospital admissions, that are simultaneously: undesirable for patients; costly to the health service; and potential markers of low-quality care.

Also known as *predictive risk models,* these tools are used widely in the health and social care system, both for:

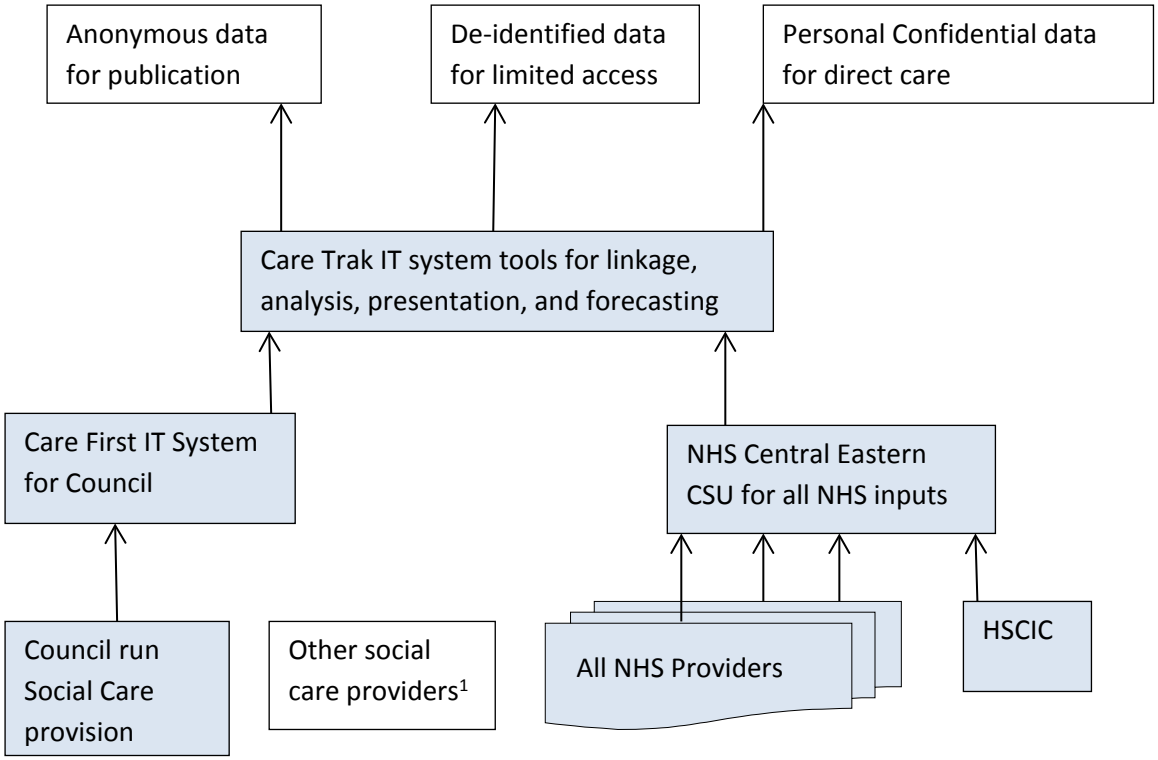
- analysing the health of a population ("risk stratification for commissioning"); and
- targeting additional preventive care interventions, such as the support of a community matron, to high-risk patients ("risk stratification for case finding").

[2] Please note this list was produced from the elaboration process over the first day of the visit

Elaboration

1. Information Architecture

   The information architecture described below emerged from the elaboration activity, it was not something that had been discussed at depth between the parties prior to the visit, but the parties were comfortable with it.



[1] The collection of social care provider data and how it would be used within the integrated care has not yet been considered in depth

It should be noted that the NHS are looking to the CSU for all their linkage, analysis, presentation and forecasting support. Social Care is looking to Care Track to provide the same. Within the integration Pioneer the Care Trak system is the preferred IT system with analysis being performed by CSU and Council staff with "super-user" [see later] rights.

ACTION 1: Southend Pioneer will confirm agreement of all parties to this model; Any changes to it especially direct flows from providers to Care Trak should be shared with the DH visiting team as it may affect the proposed solution

2. Types of data

   Three types of data emerged as needed within the Pioneer site:

   - Anonymous or aggregate data for publication, reporting and strategic planning
   - Personal confidential data which is only exposed to those health and social care professionals undertaking direct care and with whom the person [patient/client] has a legitimate relationship

- Patient level data, which is required for linkage and presentation for limited access which does not need to be identified, but may be identifiable. This could best be described as weakly pseudonymised or de-identified for limited access

3. Data Flows Previous and Aspirational

The first table below describes the situation which existed in the Southend on-Sea Pioneer site. This is not the situation now as the legal basis for the health flows was not able to be demonstrated and has therefore stopped, the social care flows continue as they are supported by the legal basis of consent [see 6 below]

A Table showing the previous data flows to support integration

Flows From	Flows to	Data Description	Identifiers
Community Provider [SEPT][5]	Care Trak	Community Events and activity inc. clinical data	TBC[1]
Mental Health Provider [SEPT][5]	Care Trak	Mental Health Events and activity inc. clinical data	TBC[1]
Acute Hospital Provider	Care Trak	Hospital activity data inc clinical data that does not flow to the HSCIC	TBC[1]
HSCIC	PCT and then to Care Trak	Data from the secondary uses service [SUS][2]	TBC[1]
GP Practice	Care Trak	Prescribing data and some clinical data[3]	TBC[1]
Southend Borough Council Care First IT system	Care Trak	Case Management file data of adults and children receiving social care involving events, activity, social care data and financial assessments[4]	TBC[1]

TBC[1] refers to the position that a detailed analysis of the identifiers has not taken place. This work will be done by the Pioneer site and the data sets provided to the DH visitors and presented in appendix 3. However it is believed that only NHS number, Care First unique ID, postcode, gender, age, and client type are the key identifiers that flow

[2] Excludes supersensitive data

[3] This was a one-off extraction and the staff member has moved on, the status of this extraction and its purpose is yet to be confirmed

[4] Only adult data flows and of those adults only those who have not opted out flows. {See section 6 re-those people deemed not to have capacity}
[5] It should be noted that SEPT does have a contract with PI the owners of CareTrak. This contract and activity is outside the integrated care pioneer scope, but may have a bearing on the information architecture hence action 1 on page 5

The table below sets out the aspirational data flows that the Pioneer site would wish to pursue. The reasons why they are wanted fall into three main groupings:

a. Risk stratification for commissioning
b. Risk stratification for case finding
c. Identifying care pathways and the type of individuals who travel them

Flows from[1]	**Flows through**	**Flows to**	**Description**	**Identifiers**
Continuing Health Care IT System in CSU	N/A	Care Trak	Assessment data on those receiving CHC	TBC[2]
SBC commissioned providers[3]	National Treatment Authority[3]	Care Trak[3]	Drug and Alcohol event, activity and clinical data[3]	TBC[2]
NHS 111	CSU	Care Trak	Event and activity data inc. clinical data from NHS 111 not onward flow services	TBC[2]
Out of Hours [OOH]	CSU	Care Trak	Event and activity data inc. clinical data from OOH	TBC[2]
Ambulance and Paramedic provider	CSU	Care Trak	Event and activity data inc. clinical data from OOH	TBC[2]
GP[3]	CSU[3]	Care Trak[3]	Event and activity data inc. clinical data in excess of care.data[3]	TBC[2]
Hospital Provider[3]	CSU[3]	Care trak[3]	Event and activity data inc. clinical data in excess of SUS/care.data[3]	TBC[2]
Any other qualified provider [health] commissioned locally	CSU	Care Trak	Event and activity data inc. clinical data	TBC[2]
Any other qualified provider [social care] commissioned locally[3]	CSU[3]	Care Trak[3]	Event and activity data inc. confidential data[3]	TBC[2]

[1] There is an assumption this data will be provided free in the volumes, scope and format as required, but it is understood that high level policy discussions are ongoing and data not flowing from the HSCIC ie direct from the provider may be subject to a charge

TBC[2] The absolute requirements have not reached consensus but must include NHS Number, some component of post code, some component of age, equality data, client type.

[3] There is more work to do within the Pioneer economy to properly specify this aspiration further than a very high level description

Action 2: The Pioneer will undertake further work to clarify the aspirational data flows and ensure it does not significantly change the information architecture

4. Dissemination
    a. Anonymous data
    It was expected that this would be put into the public domain but specifically would be targeted at commissioners and their support units for health and social care, public health, providers and the public.

    More specifically the data would be used for the Joint Strategic Needs Assessment, Strategic Plans and to focus clinical and service audit and to support Health and Wellbeing Boards.

    b. De-identified data for limited access
    This data would not be made public and access to it would be limited to certain individuals in specific roles for specific purpose under tightly controlled permissions [governance and contracts with liabilities and penalties]

    More specifically the data would be used to enable better commissioning, provision, scrutiny through the Health and Well Being Boards. Purposes may include:
        - Emergency planning [identifying the whereabouts of vulnerable adults who require early rescue service intervention]
        - Service review
        - Pathway re-design
        - Improved deployment of other services eg housing, police, fire
        - Identification of poor outcome cohorts who require at least a direct care assessment [see next section]

    c. Personal Confidential data
    This data would only be made available to a registered and regulated health or social care professional with a legitimate relationship with the person [patient/client]. There are three courses of action:

- A multi-disciplinary team assessment of the person's situation resulting in specific action by one or more members of the direct care team
- Direct action by the professional highlighted to the case management issue
- If the first two do not resolve the issue and/or highlight further issues individual funding requests or a bespoke commissioning plan may be needed. If PCD is required to be shared patient consent will be sought.

5. Potential new initiatives outside health and social care
   A number of scenarios were worked through which could potentially widen the scope of this data beyond the health and social care system for example involving police, education and other services. There was a clear consensus that there must be a legal basis for the data processing, consent was the favoured model to support both the common law duty and DPA when the type of data was personal confidential data or involved sharing de-identified data for limited access outside of the health and social care system in any agreed solution.

6. Legal basis for flows
   SBC established consent as the basis for enabling the flow of personal confidential data from their client IT system [Care First] to Care Track. They did enable a client opt out and automatically opted clients out if their family and/or care home manager deemed the patient not to have capacity. This involved 4000 clients each receiving a letter. There were some doubts about whether the recipients had been informed that their data was being processed by PI in the Care Trak system explicitly.

   Action3: The Pioneer will establish whether the clients were explicitly informed that the data processor was PI.

   In the world view going forward the scope of the data is not just the 4000 clients in receipt of services from SBC but the whole of the catchment population 175,000 and all health and social care data. As already alluded to the legal basis for flowing the NHS data and some national social care data is not apparent so the data has stopped flowing into Care Trak from the NHS.

7. Other
   a. Data Controller
      The Data Controller for the data within Care Trak appeared to have not been fully clarified. Care Trak includes health and social care data and super-users have access to both. The questions around who decides what happens to this data and who has access to this data produced some uncertainty. It would appear that SBC and the CCG and CSU may be data controllers in common.

      Action 4: The Southend Integrated Care Pioneer group will in the context of the above three actions establish and confirm Data Controller arrangements.

b. Data Governance and Contracts
There are two types of license to access the Care Trak data an "ordinary user" and a "super-user"

Super-users include the system administrator and can use all the tools and create dash boards from the analyses, organise presentations and produce forecasts.

Ordinary users can access the data down to patient level ie see the weakly pseudonymised data but cannot change anything.

Existing super-users and users in the current and previous situation have access to other information which makes full identification of the person [patient/client] possible for example SBC staffs have access to Care First so can cross reference either the Unique number or NHS number from Care Trak with those on Care First which have the full suite of identifiers present.

Action 5: The Pioneer team need to work through arrangements so that patient anonymity can be upheld in health and social care when using the controlled environment planned to be provided by Care Trak.
[This should use the experience and expertise of the CSU and any supplementary advice from the DH Visiting Team]

The table below describes the current and proposed license arrangements:

	Ordinary		Super-user	
	Now	Future	Now	Future
CCG	0	TBC	2	TBC
SBC	0	12 {panel Members]	4	TBC
CSU	0	TBC	2	TBC
SEPP	4	3	3	TBC
GP Practice	0	1 per practice =37	0	0

It was not clear whether the contract with PI for Care Trak fulfils the governance arrangements the Information Commissioners Office would like to see in place for de-identified data for limited access and as well as those set out in the "IG Toolkit". Additionally it was not clear whether the user licenses contain the liabilities and penalties which are also expected to be in place by the ICO code of anonmysation in the section on de-identified data for limited access.

ACTION 6: The Southend Integrated Care Pioneer group were going to establish sound data governance practices to assure patient anonymity. Phil Walker offered a teleconference support if so desired

c. Data Destruction Policy

Data appeared to be kept since 2008 so that trends could be observed it did appear that any data once inside the Care Trak IT system was ever destroyed

Action 7: The Pioneer team acknowledged the need for a data destruction policy and will establish one as soon as is practical

d. Research

The question of research had not surfaced within the Pioneer site as a serious discussion issue

There was a view that commissioning innovatory activity for people identified from risk stratification for case finding should be viewed as service improvement rather than research even when there is no evidence to support the service commissioned

Commissioning pathways of care was discussed on two occasions during the day, the theoretical desirability of commissioning an integrated whole set of events and activities for people with long term conditions was widely supported. The approach was twin track with a clear aspiration to have more of the second type within the Pioneer:

a) Trying to ascertain the pathway of care for individuals and then changing it as deemed necessary
b) Designing the pathway of care based on best evidence, commissioning it and measuring the variation from it and discussing reasons with the providers. There was also a vision on having a prime provider who worked with secondary providers to provide the whole pathway

Design: short timescale ~3 months

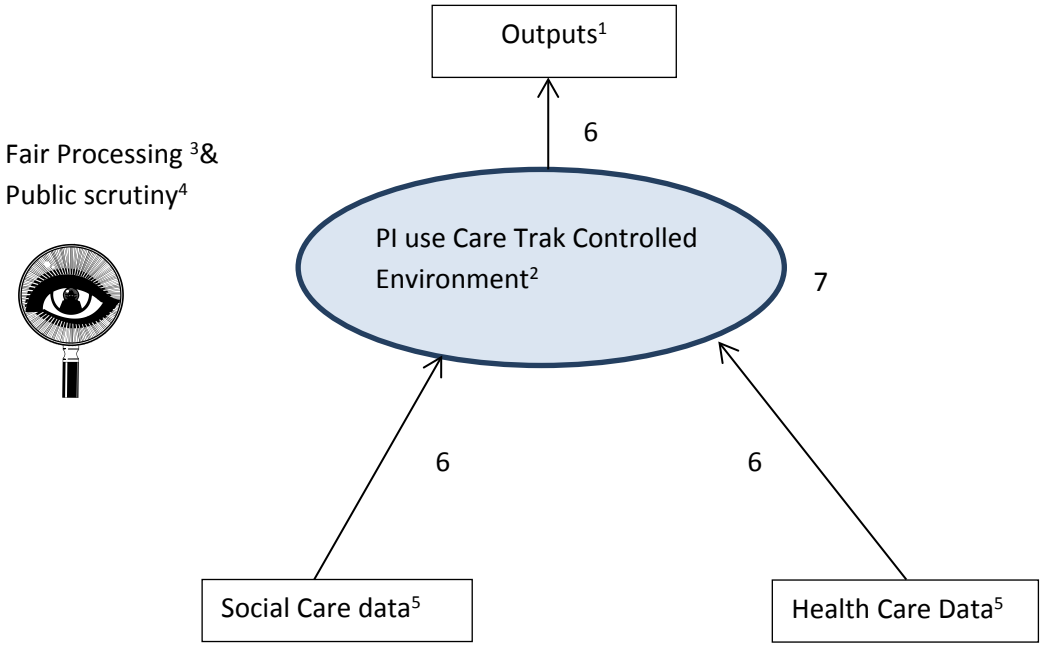
Assumptions

The current NHS England application to the Confidentiality Advisory Group is unlikely to be a successful model for supporting Pioneers as it only supports NHS organisations and data.

The proposal would support the core proposition as described in the preceding pages and diagrammatically represented by the information architecture

Additional data flows into Care Trak and from Care Trak that involve organisations outside the health and social care system would be dealt with by consent or a different legal basis to that described below

The Proposal



Explanation of Diagram	
1	Outputs will be diagrams, maps, graphs etc Age Bands, postcode stems, and NHS number will be only identifiers. NHS number will only be available to those with a direct patient care relationship with the patient or to people with the inability to re-identify and sound contracts/licenses to ensure it does not happen
2	Conforms to ICO and IG Toolkit Data Stewardship criteria set by HSCIC
3	A sound method of informing the public through multiple channels and by all participants should be in place
4	This proposal is a bespoke solution to SICP plus like Pioneers and therefore will need to be fixed term so as not to skew the market.
5	Input identifiers limited to NHS number, postcode, age, gender
6	Legal Basis of flow is a Section 251 approval
7	Data Controllers are SBC and CCG as data controllers in common

Design: Long term strategic solution ~14 months

a) Based on a new Section 251 Regulation
b) The regulation is supported by a clear policy which must include but is not limited to health and social care integration
c) Critically dependent on the ability to harmonise all the Pioneers requirements with regard to:
    a. Information architecture
    b. Purposes
    c. Scope
d) Conform to key policy decisions

Preparation

Leadership: Darren Sugg

Materials: SICP site report is available to participants before event

Attendees: Pioneers only each can have up to 3 people; an organisational leader, a professional leader, and an information governance leader

Venue: London

Agenda

1. Southend Integrated Care Pioneers: Our context and Issues [Presentation]
2. DH Visitors: Our analysis [Presentation]
3. Question and Answers
4. Group Working
    a. How do our issues compare with Southend?
    b. Is our context very different from Southend and if so does it matter?
5. Feedback and group learning
6. Proposed short and long term solutions [presentation]
7. Questions and Answers
8. Group working
    a. Would the short term solution work for us as is or with very minor tweaking?
    b. Would the long term proposal work for us, if not why not?
9. Feedback and Group Learning
10. Concluding Comments and Next Steps

Action Table

The single point of control for the DH visitors is Darren Sugg

Action	Page	Description	Responsibility
1	5	*Southend Pioneer will confirm agreement of all parties to this model; Any changes to it especially direct flows from providers to Care Trak should be shared with the DH visiting team as it may affect the proposed solution*	SICP[1]
2	8	*The Pioneer will undertake further work to clarify the aspirational data flows and ensure it does not significantly change the information architecture*	SICP[1]
3	9	*The Pioneer will establish whether the clients were explicitly informed that the data processor was PI.*	SICP[1]
4	9	*The Southend Integrated Care Pioneer group will in the context of the above three actions establish and confirm Data Controller arrangements.*	SICP[1]
5	10	*The Pioneer team need to work through arrangements so that patient anonymity can be upheld in health and social care when using the controlled environment planned to be provided by Care Trak.*	SICP[1]
6	10	*The Southend Integrated Care Pioneer group were going to establish sound data governance practices to assure patient anonymity*	SICP[1]
7	11	*The Pioneer team acknowledged the need for a data destruction policy and will establish one as soon as is practical*	SICP[1]
8	14	Darren Sugg will organise and Integrated Care Pioneers workshop ideally before the end of February	DS
9	N/A	Martin Severs will produce version 2 of the report and circulate DH team and SICP representatives via Mike Bennett. Please do not make the document public until advised to do so as commissioners of visit need to see and reflect on report	MPS
10	N/A	Phil Walker will brief Karen Wheeler and John Rouse and relevant senior colleagues	PW
11	N/A	Phil Walker will produce and lead on brief for Minister [Norman Lamb] with input from DH team	PW
12	N/A	Pending decisions PW will work with senior colleagues to progress short timescale proposal with a view of having proposal at March CAG meeting if proposal supported	PW
13	N/A	Clarify the level of public dissemination beyond participants	DS & PW

[1]SICP + Southend Integrated Care Pioneer

APPENDIX 1

Wednesday 8th January 2014			
Time (Approx.)	**Description**	**Attendees**	**Venue**
9:30 – 11:00am	Kick off Meeting/Presentation	Simon Leftley - SBC Mike Bennett – SBC Michael Barrett - SBC Paul Palmer - SBC Jane Marley – CSU Indiana Viknaraja – SBC Steve Downing – CCG Mark Golledge - CSU	Room 7.03, Civic Centre
11am – 12pm	Department of Health closed session	DoH Team	Committee Room 6, Civic Centre
12pm – 1.30pm	Lunch – **DoH Team**		Committee Room 6, Civic Centre
1.30 – 4pm	Joint Workshop	Mike Bennett - SBC Paul Palmer - SBC Michael Barrett – SBC Yvonne Campen - CCG Emma Branch – CCG Steve Downing – CCG Bill Wood - CSU Kashif Khan – PI Benchmark Mark Golledge – CSU (TBC)	[3]Committee Room 6, Civic Centre
4-5pm	(Department of Health closed summary session - if required)	Jane Marley – CSU (TBC) DoH Team	
Thursday 9th January 2014			
Time (Approx.)	**Description**	**Attendees**	**Venue**
AM	Room booked for DoH team (if required)	CSU/CCG staff available on site if required	[4]Bungay Room, Suffolk House, Baxter Avenue
12-1pm	**Lunch (Provided)**		Bungay Room, Suffolk House

Southend on-Sea Borough Council Simon Leftley – Corporate Director, Department for People Mike Bennett – Acting Group Manager, Performance & Systems Michael Barrett – Planning & Performance Manager Paul Palmer – Technical Team Leader Indirani Viknaraja – Data Governance Advisor **Southend CCG** Yvonne Campen – Deputy Chief Operating Officer Steve Downing – Head of Finance Emma Branch – Commissioning Manager	**NHS Central Eastern CSU** Paul Cook – Head of Information Governance – Essex & Herts Jane Marley – Information Governance Lead – Essex & Herts Bill Wood – Information Manager – Essex & Herts Mark Golledge – Head of Performance & Information **Department of Health** Professor Martin Severs – Health Care for Older Persons Chair of Information Standards Board & Professional Lead – Caldicott review Richard Wild – Director of Information Assurance

[3] Wi-fi access, flip chart/pens will be available

[4] Room booked all day. Wi-fi access, flip chart/pens will be available

PI Benchmark Kashif Khan – Business Analyst	Phil Walker – Information Governance Policy Lead David Riley – Dame Fiona's Independent Team Darren Sugg – Integrated Pioneer Lead Ming Tang – NHSE England

APPENDIX 2

The health and social care integration situation with regard to direct care highlighting the award winning SPOR service in the Southend Pioneer site

APPENDIX 3

Data Items that identify individuals which previously flowed to the Care Trak IT system