

Southend's Integrated
Health and Social Care
approach to information
sharing and engagement

The place

Southend is best known as a seaside resort on the north side of the Thames estuary, forty miles east of central London. With 174,000 residents, it's one of the UK's more densely populated areas with a higher than average number of frail older people over 80 and a higher than average level of deprivation, with overall life expectancy around nine years lower in the most deprived areas when compared with the least deprived areas.

Working together to tackle these challenges and improve the health and wellbeing of local residents, Southend on Sea Borough Council (the local unitary authority) and NHS Southend Clinical Commissioning Group (CCG) are working in partnership to deliver the Southend on Sea Integrated Health and Social Care pioneer programme.

Integrated Care vision and approach to information sharing

The vision of integrated health and social care in Southend involves information being shared between professionals enabling them to create a single, comprehensive care package that encapsulates all of a patient's needs. Within this overall aim, Southend's pioneer programme has a particular focus on reducing unnecessary hospital admissions and keeping patients independent in their own home for longer, driven in part by an increase in community resilience, and people taking on a bigger role in managing their own healthcare.

Southend's approach to information sharing started around 4 years ago when the local Primary Care Trusts (PCTs) worked with a 3rd party supplier (CareTrak, PI Benchmark) to link health records and case files from Social Care using the NHS number, supporting analysis for a number of initiatives such as:

The changes introduced by the 2012 Health & Social Care Act, regarding commissioning organisations holding individuals data meant this initiative was stopped, and a new approach sought. Following discussions with NHS England and a "task force" of Information Governance (IG) experts who visited Southend, it was concluded that changes to legislation were required and in the meantime a S251 application to the Confidentiality Advice Group (CAG) was necessary to restart this Southend initiative.

Following a lengthy submission process, Southend secured s251 approval for an enhancement to the existing national risk stratification approval (secured by NHS England) enabling Southend to link social care data with health records for the purposes of risk stratification. Whilst Southend's s251 application was focused on sharing of social care and health data for risk stratification purposes, the local data sharing scheme actually has two other elements to it – data sharing to support direct care (for around 4,000 individuals receiving services from both health and social care) and the use of anonymous population wide data to support commissioning and strategic planning (as shown in the information flow diagram on page 5).

- ▶ **Whole pathway for re-enablement with outcomes and readmissions identified**
- ▶ **Risk stratification**
- ▶ **Care planning for direct care for individuals**

Engaging local people

The approach to engaging and communicating with local people in Southend about the planned local data sharing agreement was developed jointly by Southend CCG and Southend Council as part of the Section 251 risk stratification approval process, with feedback from the Confidentiality Advisory Group (CAG) who considered Southend's s251 approval, playing a role in shaping the approach taken.

A key area of concern raised by the CAG was ensuring that there was sufficient awareness amongst local people of the plan to share data between GPs and Social Care for both primary and secondary uses of data, and the options and processes available to opt out of (or in to) the scheme. To address these concerns the joint communications plan was enhanced by the inclusion of public meetings, patient and voluntary group forums, local media and council publications (following a period of engagement with GP Practices and Social Care staff). Specific examples of these include:

- ▶ The launch of the data sharing plans to the public at an annual health event involving 150 people (at which positive feedback was received on the presentation evaluation forms),
- ▶ Holding meetings with members of the local voluntary sector groups to share information about the scheme which could be cascaded down to their members,
- ▶ Making data sharing a standing item on the agenda for all Patient Participation Group (PPG) meetings,
- ▶ Paying for a 'wraparound' of the cover of the local free newspaper, delivered to every household and
- ▶ Including an article in the council newsletter (Outlook) sent to every household.

To help gain the public's trust, Southend worked closely on their communications with the Clinical Lead for the project – Dr Sharon Hadley – so the 'public face' of the local data sharing scheme was a trusted Doctor, rather than an unknown Council manager. This was achieved

by the use of Dr Hadley's photograph and words in publications (alongside those of other GPs, including the CCG Chair, and Social Workers) and Dr Hadley delivering presentations on the scheme at public meetings.

In addition, local Patient Participation Groups (PPGs) were engaged early on to help develop the publicity materials used to communicate with local people. This helped ensure that the content of the communications was worded to be sensitive, in plain English, and provide clear instructions on what to do.

Alongside the communications material developed for healthcare users and the wider population, Southend also made changes to how they asked for consent (in social care) as part of the CAG approval. This involved developing a new consent form with wording specific to the new data sharing arrangement.

Throughout all of the publicity material issued online, in leaflets/posters, and to the local media, Southend CCG provided the same email, phone, and address details, for local people to use to provide feedback or air their concerns. This consistent approach made it much easier to monitor the concerns raised and to respond to these in an appropriate way. This included responding quickly to vocal opponents on social media and twitter and engaging them in an individual conversation (by email or phone, whichever worked best for the individual) specific to their concerns. This ability to manage responses quickly resulted in a number of local people publicly changing their view on the data sharing arrangement from opposition to support.

Whilst concentrated in a short period between gaining s251 approval in May and starting the process for the data sharing arrangement at the end of July, Southend's communication with local people has continued beyond the 'go live' date, with it remaining a standing agenda item for the PPG meetings and a second article in the council newsletter planned to provide an update on progress, and give real life examples of how the data sharing is already helping to improve care.

It is hoped that this continued communication with local people will reassure those who have decided not to opt out and encourage anyone who has opted out to consider opting back in again. However, early indications from a snap survey carried out by the local newspaper (The Echo), just one day after the data sharing went live, are that very few patients are choosing to opt out of the data sharing process, as only 2 opt outs had been recorded by a local GP practice with over 3,300 registered patients.¹

Lessons Learnt

Key learning from Southend's engagement of local people and key stakeholders includes:

► **Confusion with Care.data** in the local and national media resulted in concerns being raised by local people about potential impacts of the local data sharing scheme which actually went beyond its planned scope. For example, concerns were raised about selling of personal data to third parties.

► **The potential for misinterpretation, or misunderstanding, of the language** used to describe the reasons for sharing information means that there is a need for communications about the scheme to not only be very clear about what the data sharing will involve, but also what the data sharing scheme is not about, for example, no financial targets.. As in Southend, whilst care was taken to explain their local data sharing scheme to people using clear and accessible explanations, the scheme was described more formally in council / CCG minutes and the s251 submission. This included a reference to identifying and reviewing the care of 'high-cost patients'. This term was misinterpreted or misunderstood by the media and local people and created concern that the Southend data sharing scheme was purely financially driven and focused on saving money, rather than improving quality of care.

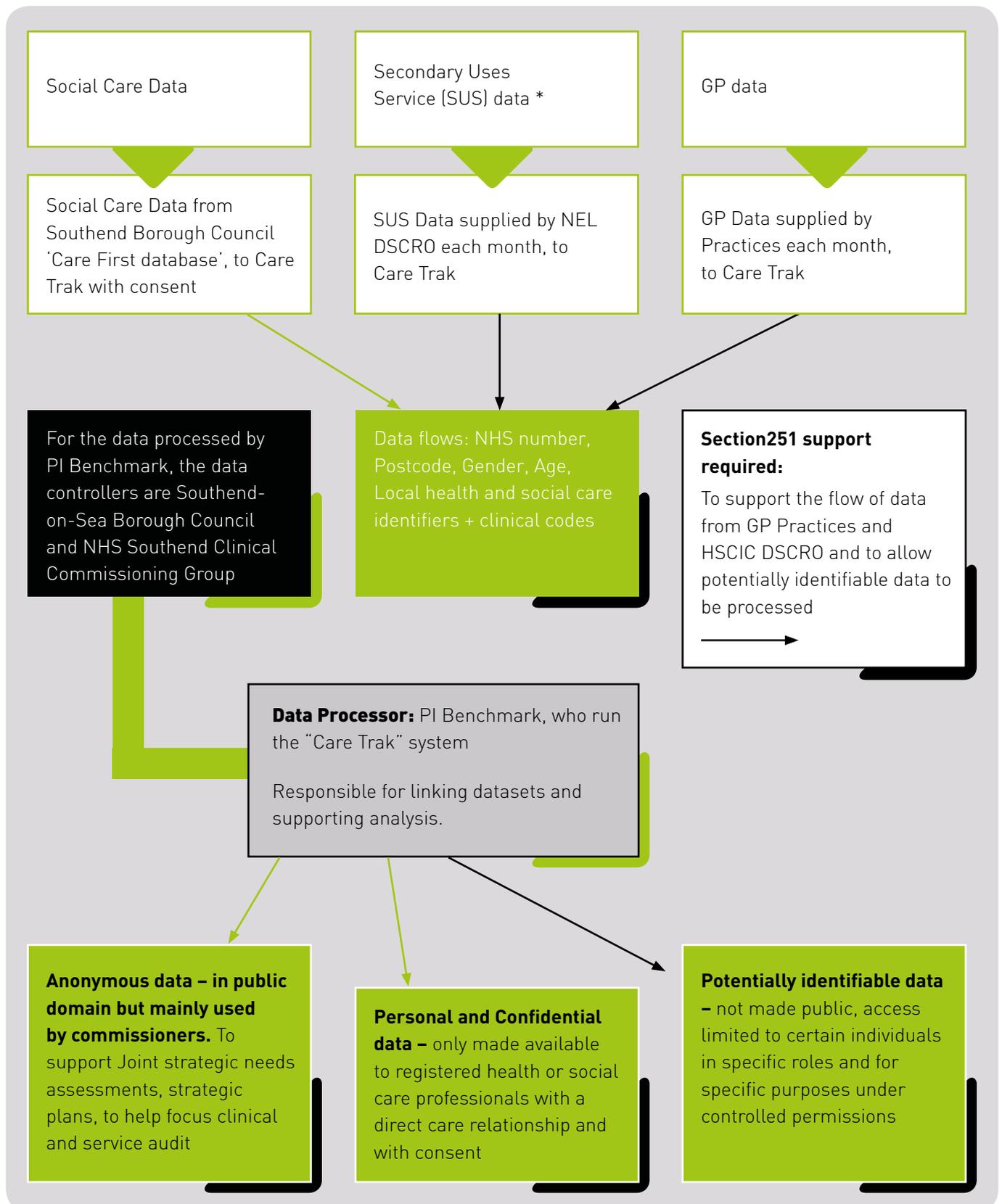
► **Relationship building with local community groups, campaigners and the local media**, combined with consistent and regular engagement with patient forums helped to limit impact of negative national press. When the news stories broke in the national media, the CCG was able to use the links it had made with patient groups and community sector representatives to talk through concerns raised by national media, and keep the conversations flowing.

► **Relationship building activity should ideally be built into a wider programme** of engagement rather than specific to the information sharing scheme. For example, in Southend, relationship building with community champions / campaigners is happening across the board (not just related to data sharing) with CCG senior staff including the Chief Officer and Head of Communications meeting campaigners to listen to their concerns, build trust and explain what the CCG does and its role in the new structures of the NHS. This activity is making a difference as the CCG is now engaging more positively with campaigners.

► Having raised awareness of the plans to share data, consideration now needs to be given as to how to **manage local people's expectations**, in particular expectations of social care patients who have proactively consented to their information being shared. As there is the potential, in some cases, for someone who has given consent for sharing, or decided not to opt out, not to have their records shared if their GP practice isn't participating in the local data sharing scheme.

¹ Echo online, 29 July 15 http://www.echo-news.co.uk/news/13504305.Is_sharing_patient_data_a_big_deal/

Diagram showing data sources, data flows, key identifiers and where s.251 approval is required.



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