Information sharing to support integrated care: Outcomes of a programme of webinars and workshops

NHS England Better Care Fund in association with North of England Commissioning Support Unit

Final report detailing the findings, conclusions and recommendations from a series of webinars and regional workshops aimed at raising awareness of appropriate information sharing practices to support direct care and non-direct care purposes.

31 March 2016
Acknowledgments

The NECS project team would like to thank Mary Hill and Rosie Seymour at NHS England (NHSE) and the Better Care Fund Support team for the opportunity to deliver this contract on their behalf.

The successful completion of this project could not have been accomplished without the expert support and collaboration of key people and organisations including; Mark Golledge of the Local Government Association, Suzanne Lea, Phil Walker and Stephen Elgar of the Information Governance Alliance (IGA) and Claire Everitt, Stuart Bolton, Emma Hart, Holly-Marie Draper and Joanna Huxton of the Centre of Excellence for Information Sharing.

Additionally we would like to express our sincere gratitude to speakers not already mentioned above namely; Ian Townsend and Peter Kidd of NHSE Interoperability programme, Debbie Terry and Shane Dark of IGA, David Stone of Kaleidoscope Consulting, Tommy Denning and David Knight of the Department of Health, Jon Devonport of Informatics Merseyside, David Hobson of East and North Hertfordshire CCG and Mike Woodhall of Midlands and Lancashire CSU.

Of course, the delivery of the project was a team effort and therefore our thanks are also extended to key individuals at NECS for their own individual contributions; Lesley Currer, Lynn Finlay, Ailsa Foggon; Lynne Cooke, David Blanchard, Andrew Robson, Ben Murphy, Lee Hogan, Sheena McGeorge, Alison Gent and all others that contributed or provided support indirectly.

Last but not least thank you to all those that have participated or attended any of our events. All of your contributions, comments and feedback have been invaluable and will influence and shape the future work programmes in this complex and ever changing environment that is Information Sharing.

Our warmest regards

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On behalf of North of England Commissioning Support
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1. **Background**

1.1 In 2015, the Better Care Fund commissioned the North of England Commissioning Support Unit to deliver a series of webinars and workshops to improve awareness in relation to information sharing for integrated care.

1.2 As part of a readiness survey in March 2015 and a follow on data sharing survey in June 2015, the Better Care Support Team identified a number of key challenges in relation to data sharing to support programmes of integrated care. This included issues relating to systems interoperability, information sharing for direct care and information sharing for non-direct care and commissioning purposes.

1.3 In order to better support local organisations in this area, the Better Care Support Team commissioned the following events:

- Information Sharing for Integrated Care Webinar – to share current national guidance and developments in information sharing
- Information Sharing for Direct Care Workshops – a series of six workshops, to share best practice and case studies in relation to information sharing for direct care purposes and to explore current issues and enablers for improving information sharing for direct care
- Information Sharing for Non-Direct Care and Commissioning Workshops – a series of three workshops, to share best practice and case studies in relation to information sharing for non-direct care purposes and to explore current issues and enablers for improving information sharing for commissioning and non-direct care purposes
- Information Sharing Feedback Webinar – to provide feedback from workshop speakers on their reflections from the workshops and some of the key themes emerging from the workshops

2. **Purpose and scope of report**

2.1 The purpose of this report is to present key findings, feedback, observations and reflections from the webinars and workshops to inform the Better Care Support Teams future service delivery planning in relation to information sharing to support integrated care. It also identifies a series of recommendations developed from the key issues emerging during the workshops to progress with other national, regional and local organisations working in this area currently.
2.2 This report will be published through current integrated care and IG communication channels as one of a number of agreed products resulting from the delivery of this programme of webinars and workshops.

3. Key themes

3.1 Introductory webinar – December 2015

3.1.1 This webinar was carried out to introduce some key national guidance established to support information sharing for integrated care (the Information Sharing User Framework and the Five Step Blueprint) and to introduce attendees to some of the national organisations working to improve information sharing in relation to integrated care. It also provided details of the information sharing workshops to be delivered during early 2016.

3.1.2 253 people registered for the webinar of which 143 participated. The slides and recording were made available on the NECS website at http://www.necsu.nhs.uk/necs-news/integration-information-sharing-webinar-and-events-1971 as well as being shared directly with all registrants.

3.1.3 Of the 143 that participated in the webinar, 69 completed the evaluation afterwards. Of those that completed the evaluation, 23 were representatives from local government, 39 were from NHS and 7 from other organisations. There was equal spread of roles across information governance, information security and integrated care programme leads.

In terms of overall rating of the webinar out of 5 (5 being excellent) those that completed an evaluation gave a positive average rating of 4.2 with comments that included:

“It was a really good webinar - we need more of these as and when developments occur. It would have been great to have had this in place before now as our project has been running for 12 months now”

“I found the seminar very helpful. I was impressed by some of the good work that’s been done to make sense of the IG challenges (e.g. the 6 types of sharing straight away helps structure the thinking, dialogue and planning). Very practical. Very much worth delivering this as a presentation as it provides a clear route into the wealth of material that has been produced and how it all fits together. Agree confirming the legal basis for different sharing activities is something worth doing centrally”

“Excellent! Many thanks. Sharing the learning will save us weeks, months and possibly years of effort”
A more detailed summary of the feedback received is shown in figure 1 below and in appendix 1 – webinar evaluation.

Figure 1: Summary of webinar evaluation

<table>
<thead>
<tr>
<th>Section evaluation (average out of 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you rate the introduction?</td>
</tr>
<tr>
<td>How useful was the introduction to CofE?</td>
</tr>
<tr>
<td>How useful was the overview of the new Information Sharing User Framework?</td>
</tr>
<tr>
<td>How useful do you feel the information provided will be to implement...</td>
</tr>
<tr>
<td>How useful was the overview of the 5 Step Blueprint?</td>
</tr>
<tr>
<td>Overall how would you rate the introductory webinar?</td>
</tr>
<tr>
<td>How likely is it that you will attend a regional workshop?</td>
</tr>
</tbody>
</table>

3.1.4 As part of the webinar evaluation and question and answers session, attendees were asked to comment on what areas they would like included in the forthcoming workshops so that these could be tailored to reflect these.

A number of suggestions were included, some specific to direct care or a commissioning purpose, but many covering all areas of information sharing. These included the following topic areas:

- Consent
- Legal basis for information sharing for different purposes
- Legal basis for sharing information between key organisations
- Interoperability and sharing between systems
- Contracting and data controller responsibilities
- Templates and toolkits for key documents
- Engagement with patients and service users
- Engagement with other organisations and key stakeholders
- Culture change
- Case studies of where effective information sharing has been implemented
- Consistent use of NHS number
- Sharing outside of health and social care (voluntary/private)

A further breakdown of requested content for the workshops is shown in appendix 2 broken down by workshop topic area.
The majority of these topics were picked up during the relevant workshops and any further guidance or support needed was identified as part of discussions within the workshops (see sections below).

3.1.5 Additional questions were raised during the webinar and were either actioned during the webinar or within the workshop content.

3.2 Regional Workshop 1 – Information Sharing for Direct Care

3.2.1 Six regional workshops were carried out across the country in January 2016 to share learning and good practice in relation to information sharing for direct care.

Although there has always been a need to share information appropriately for the purpose of managing care for patients and service users, the changing landscape of the NHS and social care introduced through the Health and Social Care Act, the increased focus on personalisation and integrated care highlighted through the Five Year Forward View, and the ongoing work in relation to integrated digital care records, has led to a more complex landscape in relation to information sharing for direct care and highlighted the need for clear and consistent guidance to support local areas delivering this information sharing agenda.

The Information Sharing to support Direct Care regional workshops were therefore established to:

- Provide practical tools and guidance to organisations carrying out information sharing to support direct care
- Share examples of good practice from local areas already implementing effective information sharing to support direct care
- Explore some of the enablers and barriers to effective information sharing currently

3.2.2 There were 240 spaces made available for the direct care workshops across six different regions (Leeds, Manchester, Birmingham, Bristol, Nottingham and London). 230 people registered for the workshops of which 194 attended. The slides have been made available on the NECS website at [http://www.necsu.nhs.uk/necs-news/necs-workshop-supporting-materials-2145](http://www.necsu.nhs.uk/necs-news/necs-workshop-supporting-materials-2145) and shared directly with all registrants.

3.2.3 Attendees of the workshops consisted of a mix between LA, CCG, NHS Provider, NHSE, Health & Social Care Information Centre (HSCIC), private sector healthcare providers, 3rd sector and a few private sector system providers.

Across the 151 health and wellbeing board areas, a broad spectrum (approximately 120) were represented by attendees at the workshops.
A summary of attendees is contained within the attendance and evaluation report in appendix 3.

3.2.4 Summary of the evaluations demonstrated a clear indication that the content and delivery of the workshops was very well received and appreciated. They also identified the need and desire for further opportunities for networking, cascading expert opinions and advice and sharing best practice and local outcomes or successes.

Out of 119 evaluations received, 98.2% described the workshops positively. The most frequently used words were; useful, interesting, worthwhile, beneficial, practical, thought provoking and valuable.

Out of 6 (6 being excellent), attendees rated the overall event as 4.9. Attendees also stated that out of 6 again, the workshop improved their ability or understanding (4.2) and that they were now more likely to implement changes as a result of attending (4.2).

Comments made in the evaluation feedback included:

“A practical and useful workshop identifying what national guidance is available (or planned) and help that is available from local communities / best practice (e.g. Vanguard sites)”

“Useful session, good for networking and gaining ideas/ opinions from other peers. Able to regain focus.”

“Workshop on risk stratification will be useful”

“Really great course, I look forward to the commissioning event”

“Helpful and useful workshop, clear what needs to happen, just needs to happen”

“I have to say I got an enormous amount out of the workshop on Monday - it was so good to meet people who are actually doing what we want to do here …, and the fact that those people were mostly governance based was brilliant - they've gone through the difficult stuff. Really encouraging.”

A full summary of the evaluations received is included in figure 2 below and in appendix 3.
3.2.5 Central to these workshops was the intention to understand local issues in delivering information sharing to support direct care purposes whilst at the same time capturing ideas and examples of best practice and ways of improving information sharing for direct care moving forward. Full details of the finding of these discussions are included in section 3.4.

3.3 Regional Workshop 2 – Non-Direct Care

3.3.1 This workshop was carried out to share learning in relation to information sharing to support commissioning and non-direct care purposes. In particular, it aimed to:

- Provide practical tools and guidance to organisations carrying out information sharing to support commissioning and non-direct care
- Share examples of good practice from local areas already implementing effective information sharing in this area
- Explore some of the enablers and barriers to effective information sharing at the present time

These workshops provided attendees with the opportunity to hear from national leads at the Department of Health and the Information Governance Alliance in relation to the current national context around information sharing for commissioning and non-direct care and explore some of the key challenges in relation to data linkage programmes. It was aimed at information governance, information sharing and programme leads involved in commissioning integrated care programmes including health and local authority commissioners, but also anybody who was involved in improving practices around information sharing for commissioning and non-direct care purposes.
3.3.2 130 people registered for the workshop of which 93 attended. Some of those registered on the workshop reported that they could not attend due to competing work demands, including the completion of the Better Care Fund Template which coincided with the timing of the workshops.

The slides referred to during workshop two have also been made available on the NECS website at [http://www.necsu.nhs.uk/necs-news/necs-workshop-supporting-materials-2145](http://www.necsu.nhs.uk/necs-news/necs-workshop-supporting-materials-2145) and shared directly with all registrants.

3.3.3 Attendees of the workshops consisted of a mix between LA, CCG, NHS Provider, NHSE, HSCIC and 3rd sector organisations.

Again, across the 151 health and wellbeing board areas, a broad spectrum of areas was reached, with 79 regions boards being represented by one or more attendee (where attendees indicated their region).

A summary of attendees is contained within appendix 4 (W2 Attendance and evaluations)

3.3.4 Summary of the evaluations demonstrated that the content and delivery of the workshops was again very well received and appreciated. However, they also indicate a degree of frustration due to the lack of progress and clarity nationally whilst the announcements/report from Dame Fiona Caldicott was awaited.

They also identified the need and desire for further opportunities for networking, cascading expert opinions and advice and sharing best practice and local outcomes or successes.

Out of 57 evaluations received, 89% of the words used to describe the workshop were positive. The most frequently used words were; Interesting, Useful, Thought Provoking, Worthwhile, Beneficial, Valuable, Challenging, Practical and Stimulating. Those that used negative words to describe the workshops used words such as confusing, frustrating and then some which were aimed at the delivery which they found to be over ambitious and rushed. Whilst these comments in the evaluations were a minority, they reflected to some extent, the issues noted during the round table discussions and are referenced in greater detail in the barriers, enablers and reflections in section 3.4.

Regardless of these frustrations though, out of 6 (6 being excellent), attendees rated the overall event as 4.6, and that out of 6 again the workshop improved their ability or understanding (3.9) and they are now more likely to implement changes as a result of attending (4.1).

Other comments fed back as part of the evaluation included:
“It was all helpful although the case example from Hertfordshire was useful”

“The government needs to provide the framework to enable organisations to carry out its integration agenda instead of not having to pay workarounds”

“I was looking for answers - they are still not there”

“Thank you so much for making the effort to accommodate my needs”

“Thank you for yet another good event”

A full summary of the evaluations received is included in figure 3 below and in appendix 4.

Figure 3: Summary of workshop 2 evaluation

![Overall content & delivery (average out of 6)]

3.3.5 As mentioned with the direct care workshops, central to these workshops was the intention to understand local issues in delivering information sharing to support non-direct care and commissioning purposes, whilst at the same time capturing ideas and examples of best practice and ways of improving information sharing for non-direct care moving forward. Full details of the finding of these discussions are included in section 3.4 below.

3.4 Barriers, Enablers and Key Themes

3.4.1 Round table discussions in each of the workshops, asked attendees to reflect on specific barriers to information sharing, whilst at the same time considering how these may be overcome and ways of improving information sharing moving forward.
3.4.2 These discussions focused on the information sharing purposes being covered in the relevant workshop e.g. direct care or non-direct care purposes, with the final two workshops specifically exploring issues in relation to information sharing for planning, financial modelling, outcomes tracking and risk stratification.

3.4.3 Figure 4 provides an overview of the different types of issues being identified across the direct and non-direct care information sharing purposes. Concerns were raised around a lack of coherence in approach and guidance across organisational boundaries and organisational types and also difficulties in information sharing across geographical boundaries.

Figure 4: Barriers to Information Sharing

3.4.4 There was a clear message about a lack of understanding in the system in relation to what can and can’t be shared and with who, and the need for consistent, clear guidance, with standardised terminology across organisations and sectors.

3.4.5 Cultural issues were also identified, with IG sometimes being quoted as a barrier to information sharing, and evidence of a fear of sharing due to potential implications of getting it wrong. There was also a strong feeling that IG teams were not being incorporated into new programmes of information sharing at an early enough stage, to ensure that any specific issues or approaches could be discussed and agreed.

3.4.6 Resources were also seen as an issue, whether that be in terms of funding or relevant skills availability, and the ability to be responsive to new national initiatives was seen as being hampered for local areas by this lack of resources. Systems incompatibility was quoted as an additional complication in sharing effectively, with systems also not being able to record consent
decisions effectively or changes needed to systems not being implemented due to difficulties in implementing timely contract changes.

3.4.7 However, on the flip side to the discussion relating to barriers, it was clear that many areas were making effective progress in implementing methods of information sharing to support direct care and commissioning.

3.4.8 Speakers from local areas provided positive examples of local developments in this area and attendees also highlighted a number of examples of good practice in their own areas.

3.4.9 The group discussions identified what factors would, or are, enabling more effective information sharing and figure 5 summarises these. To some extent these mirrored the barriers, in that what was seen as key to improvements in this area, was a clear consistent national documented approach to information sharing across the different purposes. It was suggested that a “kitemark” system should be implemented to demonstrate that guidance had been approved by the key national bodies, potentially through the Information Governance Alliance.

**Figure 5: Enablers to Information Sharing**

<table>
<thead>
<tr>
<th>National Approach</th>
<th>Leadership</th>
<th>Awareness</th>
<th>Systems</th>
<th>Citizen Particip.</th>
<th>Shared Learning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear Message</td>
<td>Clear governance</td>
<td>Legal basis in Plain English</td>
<td>How to guides</td>
<td>Positive case studies</td>
<td>Opportunities for shared learning</td>
</tr>
<tr>
<td>Comms</td>
<td>Courageous Leadership</td>
<td>Case studies</td>
<td>Current digital footprint</td>
<td>Clear comms/ Transparency</td>
<td>Collaborative Tools</td>
</tr>
<tr>
<td></td>
<td>Collaborative working</td>
<td>Unified terminology</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.4.10 Leadership was seen as key and terms such as “champions” and “courageous leadership” were used to describe a more positive proactive approach to leading this agenda, with more opportunities for collaborative working and collaboration.

3.4.11 No one solution was identified as being able to resolve system interoperability concerns, but it was clear that it would helpful to have some technical guides to support further work in this area and a clear understanding of how different areas were progressing in their digital footprint.
3.4.12 Transparency was also seen as key to information sharing, and the patient/service user role was seen as central in terms of ensuring that positive case studies of information sharing could be developed and citizens could be fully involved in the development of improved information sharing solutions.

3.4.13 In addition to the more general barriers and enablers highlighted above, some key issues and concerns were raised around some of the specific commissioning/non-direct care purposes and these are summarised in figure 6 below. However, the knowledge levels on these different purposes was limited in those attending and therefore further work may be needed to identify better ways of working in these specific areas.

**Figure 6: Key issues re commissioning purposes**

3.5 **Summary feedback webinar**

3.5.1 This webinar was carried out to:

- Provide feedback on the outcomes of the regional workshops
- Provide reflections from the workshop speakers
- To signpost attendees to information on the guidance and organisations included in the workshops
- Give an overview of some of the key themes coming out of the different events

3.5.2 95 people registered for the webinar of which 61 participated. The slides and recording were made available on the NECS website and shared with all registrants.

3.5.3 Summary of evaluations demonstrated that the content and the delivery of the webinar was very well received and appreciated. Of the evaluations received out of 6 (6 being excellent) attendees rated the overall event as 4.9. In particular attendees found the signposting and the overview of the barriers and enablers beneficial.

**Figure 7: Summary of feedback webinar evaluations**

<table>
<thead>
<tr>
<th>Category</th>
<th>Rating</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall opinion of webinar</td>
<td>4.9</td>
<td></td>
</tr>
<tr>
<td>BCF Introductions</td>
<td>4.7</td>
<td></td>
</tr>
<tr>
<td>NECS Barriers and enablers</td>
<td>5.3</td>
<td></td>
</tr>
<tr>
<td>LGA Reflections</td>
<td>4.8</td>
<td></td>
</tr>
<tr>
<td>IGA Reflections</td>
<td>4.4</td>
<td></td>
</tr>
<tr>
<td>CoC Reflections</td>
<td>4.3</td>
<td></td>
</tr>
<tr>
<td>Q&amp;A</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Signposting</td>
<td>5.1</td>
<td></td>
</tr>
</tbody>
</table>

3.5.4 Of the 56 people that attended the webinar, 8 people submitted an evaluation which means that feedback was limited. However, of the comments that were received these reflected those that have been captured in previous sessions and reinforced the desire for further signposting, support and guidance moving forwards.

Final comments: “Really insightful session. Well done”

Most useful: “Update on feedback from regional workshops as I had not been able to attend any”

Further support required: “Clarity on the resources available to support local areas with developing information sharing approach”

3.5.5 Additional questions were raised during the webinar and were actioned during the webinar.
4. **Conclusions**

4.1 Overall these information sharing events were received very well, with attendance being high, feedback being very positive and a strong indication that professionals working in IG and integrated care wish to be involved in further developments and events.

4.2 It identified a number of areas where information sharing continues to be a challenge in the implementation of integrated care initiatives and in linking data to support non-direct care and commissioning purposes.

4.3 It was clear that further guidance, support and improved ways of working were needed to ensure that local areas could effectively identify appropriate methods for linking and sharing data and a potential need for changes to current methods of data collection to support that e.g. through the HSCIC Data Services for Commissioners Programme.

4.4 A clear indication was given that further examples of good practice should be shared to ensure that those areas, currently facing challenges in implementing appropriate information sharing solutions can learn from those who have made progress in relation to this.

4.5 It was also clear that proactive engagement and good governance structures were key to this process and the workshops allowed attendees to understand methods for effectively engaging with patients, service users and partner organisations.

4.4 The feedback provided by attendees have allowed a number of recommendations to be identified to ensure improved opportunities for collaboration and appropriate data sharing at all levels.
5. Recommendations

5.1 Based on the findings from these information sharing events, we recommend that the Better Care Support Team should work with other key national organisations and programmes involved in improving information sharing for integrated care, including the Information Governance Alliance, Centre of Excellence for Information Sharing, Local Government Association, NHS England, the Health and Social Care Information Centre and the Department of Health to:

- Develop further case studies of positive information sharing practices identified from attendees at the workshop and share with local information sharing organisations
- Agree a consistent approach for delivering guidance across national organisations building on the guidance and template materials already included in the Information Sharing Framework and the Five Step Blueprint
- Work with the Centre of Excellence for Information Sharing to ensure knowledge and best practice on engaging with citizens and information sharing partners is disseminated broadly to those involved in the integrated care agenda
- Through the Better Care regional teams and working with the local Strategic Information Governance Networks (SIGN), ensure support is provided to local areas to develop appropriate governance structures and strong leadership to support improved information sharing practices
- Ensure information and updates in relation to key national programmes that impact on information sharing practices such as the Interoperability programme and the Data Sharing for Commissioners Programme is disseminated to integrated care and information sharing leads locally
- Identify other opportunities to explore ongoing issues in relation to information sharing for specific commissioning purposes and potential best practice and solutions in this area
- Identify further opportunities for signposting, networking, cascading expert opinions and advice and sharing best practice and local outcomes or successes.
6. Appendices

All appendices can be found at: [http://www.necsu.nhs.uk/necs-news/necs-workshop-supporting-materials-2145](http://www.necsu.nhs.uk/necs-news/necs-workshop-supporting-materials-2145)

Appendix 1 – Webinar evaluation

Appendix 2 – Webinar participant content wish list

Appendix 3 – Workshop 1 Attendance and evaluation

Appendix 4 – Workshop 2 Attendance and evaluation

Appendix 5 – Summary webinar evaluation