



Great North Care Record Public Engagement
September to December 2017

Local Healthwatch in North East and Cumbria
Connecting Health Cities
Teesside University

Evaluation Report

Michelle Thompson BEM
m.thompson@healthwatchdarlington.co.uk

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1. Introduction

The Great North Care Record (GNCR) is a regional Integrated Digital Care Record programme for the people of the North East and North Cumbria (NENC), covering a population of 3.6 million people. The GNCR aims to produce a platform to join up records in front line care with an analytics platform to be shared by the NHS, Local Authorities, Universities and other health and care related organisations. The improved access to information for care will help make the North East and North Cumbria the safest place in the world to get care and the best place in the world to do research.

Between January 2017 and April 2017, Connecting Health Cities (CHC) were keen to pilot three focus groups in Darlington in partnership with Teesside University and Healthwatch Darlington (HWD) in order to explore the following:

- Understand the views on current and future models of consent for use of information.
- Provide information on the constraints of current practice with regard to information sharing at the point of care, planning and research, and the potential issues caused.
- Gain feedback on people’s views and “tolerance levels” of how information sharing may develop going forward.

HWD were asked to identify, contact and facilitate three focus groups using local engagement structures with a diversity of groups including Black, Minority and Ethnic (BME) communities, older people and families. We used existing channels to ensure that the views of patients, carers and the public in the local area had an equal opportunity to voice their opinions.

We assisted in the design of a presentation and a questionnaire for Teesside University and the CHC team to trial with our focus groups. Teesside University also had to ensure their ethics process was approved before the focus groups could take place.

The focus groups were launched in May 2017 and provided a snapshot of discussions to inform the ongoing CHC programme and the future development of the GNCR across the region. Participants were provided with information packs to use for guidance during the focus groups and to explore whether they understood the concept being presented to them and the questions being asked.

An evaluation report was published by HWD for the CHC team and due to the success of the pilot focus groups in Darlington, CHC asked HWD to lead on a consent model engagement project with the other 12 local Healthwatch (LHW) who cover the NENC area, to obtain a wide and diverse range of views.

2. The Engagement Project

HWD liaised with all 12 LHW who covered the NENC area including:

- | | | |
|------------------|-------------------|-----------------------|
| 1. County Durham | 5. Middlesbrough | 9. Redcar & Cleveland |
| 2. Cumbria | 6. Newcastle | 10. South Tyneside |
| 3. Gateshead | 7. North Tyneside | 11. Stockton on Tees |
| 4. Hartlepool | 8. Northumberland | 12. Sunderland |

HWD agreed to provide the following:

- **LHW** - provide all 12 LHW with a robust proposal, MOU and budget including expectations and timescales.
- **Speaker Management** - manage CHC speaker expectations and ensure appropriate and mutually agreed timescales are pencilled in for each LHW.
- **Workshop** - manage Teesside Uni. expectations and ensure appropriate and mutually agreed timescales are pencilled in for each LHW.
- **Review** - regular reviews of the other 12 LHW to ensure activities with patient, carers and public representatives result in maximum opportunities for involvement.
- **Facilitator Packs** - provide each LHW with the appropriate information to facilitate discussions with their focus groups to achieve seamless events including.

All LHW agreed to the proposal put forward for the next phase of engagement which was led by HWD and included a Memorandum of Understanding:

For all LHW:

- Commit to the decisions already taken to set up the project;
- Identify the proposed methods of engagement within their community;
- Participate and assist the Project Coordinator Healthwatch Darlington, to complete any and all tasks relevant to the project brief;
- Support the completion of a project evaluation report by each LHW by responding in a timely manner when required.

For lead partners:

- The CHC team were responsible for holding all funds and making payments upon receipt of invoice requests from individual LHW;
- Healthwatch Darlington supported all LHW in ensuring the project had clear aims and objectives and was completed on time and within budget.

a) Resources

Resources were provided by the CHC team, Teesside University and HWD as follows:

CHC Team

- Printed participation packs for all attendees at each event.
- A copy of the CHC PowerPoint presentation on a web link and memory stick.

Teesside University

- Copies of consent forms for participants at each event (included in the participation packs)
- Recording device for anonymised recording during the workshop session (subject to consent being given by participants)

Healthwatch Darlington

- Online facilitator pack including:
 - Consent model information and rationale for facilitators
 - Information leaflets
 - Useful resources for further information
 - Ground rules and brief for focus group facilitator
 - HWD contact names and numbers

- Evaluation documentation to report back to HWD for each focus group
- Suggested event setup and checklist
- Post-event attendee survey

Local Healthwatch were expected to provide the following:

- Participants
- Venue
- Refreshments
- Laptop, Projector, Screen and Speakers
- Printouts of the post-event attendee survey, signing in sheet and focus group ground rules.
- Evaluation of the event/focus group including the post-event attendee surveys and facilitator observations.

b) Communication Strategy

All partners used the information provided to publicise engagement opportunities through their networks. HWD ensured that all partners received regular information and updates throughout the project including from CHC and Teesside University.

Suggested priority groups were:

- Long Term Health Conditions
- Young people
- Professionals/Working Population
- Condition specific groups (e.g. COPD etc)
- Maternity services (young mothers/families groups)
- Carers
- Complex needs (drug, alcohol etc.)

c) LHW Budget

Each of the 12 LHW were given a budget of £1000 to cover costs for holding focus groups or a one off event to capture the views of approx. 40 people in their area. Payment was made direct from CHC to each LHW upon raising individual invoices.

This was based on a rolling scale to include:

- 10 people - £250
- 20 people - £500
- 30 people - £750
- 40 people - £1000

d) Engagement Events Agenda

21 events were planned with 20 taking place. The last planned event in Cumbria had to be cancelled due to inclement weather. Each event had the same agenda with the same objectives and a total of 324 people attended across the region. The objectives and public agenda were as follows:

- We learn about the Great North Care Record and what it means for us.
- We discover what is meant by a “model of consent” for information sharing.

- We understand the current limitations of information sharing at the point of care, planning and research and the potential issues.
- We give our views and “tolerance levels” of how information sharing may develop going forward.
- We have our say by working together.
- We understand more about how individuals can use their voice to influence change.

Introductions & welcome LHW
Presentation by Connected Health Cities explaining the rationale, form and function of the Great North Care Record
Brief Question and Answer session (CHC will then leave the room)
Great North Care Record Workshop lead by Teesside University
CHC returns to answer any technical questions that have arisen during the workshop.
Thanks and Close
Coffee and Networking

3. Evaluation of the Project

a) HWD, CHC and Teesside University

HWD were pleased with the overall project which met all the specified requirements and goals as set out by CHC in our initial agreement. Early communications regarding diary entries were a little challenging due to the number of events needed to make the engagement meaningful. This was soon resolved once the CHC team were clear on who could be in attendance at which event. HWD were very appreciative of the time and effort the CHC team and Teesside University made in ensuring all events were covered as well as the patience of the CHC office team who were often printing out participation packs at the eleventh hour!

All LHW delivered within the time specified and adhered to the brief using all the information provided by HWD. Individual evaluation reports for each engagement event were compiled and sent to CHC in a timely manner to ensure any lessons learned from each event or focus group were rectified for the following engagement events. Small amendments to the presentations or language used were listened to and acted upon by the CHC and Teesside University presenters and facilitators. In addition, feedback from the CHC team to LHW regarding any technical hiccups were communicated quickly and effectively to the respective LHW who ensured they were improved at the next event.

LHW invoices were approved and paid swiftly once the CHC team had received the evaluation reports which was much appreciated especially by the smaller LHW.

HWD would like to thank the CHC team and Teesside University on behalf of the whole of the LHW network in the region for their professional, efficient and friendly approach to this engagement project.

b) HWD and Local Healthwatch

HWD ensured prior to the commencement of the project, that all LHW across the North East and Cumbria understood and agreed:

- Each partner would work together in a co-ordinated and timely fashion for the fulfilment of the project.
- Each partner would co-operate with the CHC Team, Teesside University and Healthwatch Darlington.
- Each partner would participate in the project. Where partners were unable to participate they would let Healthwatch Darlington know.

Although diary entries were rather challenging at the time, HWD were pleased with the way all LHW communicated across the region. This was particularly important with neighbouring LHW who considered travel distance for the CHC and Teesside University team when booking their own focus group venues and those of their neighbours. HWD managed communications including any problems or queries with regular email updates throughout the project to remind LHW teams what was required and when.

There were one or two miscommunications regarding LHW team members with limited knowledge of the project being asked to deliver the focus groups. This was due to either new LHW team members or changes to the team midway. However, this was quickly dealt with by HWD who ensured each LHW team member was familiar with the participation pack and facilitation pack prior to each focus group to ensure everything was fully understood and each event could run smoothly. Each focus group evaluation report was forwarded onto CHC in a timely manner to ensure any tweaks to the events could be actioned straightaway for the next focus group.

HWD really enjoyed co-ordinating this project and would like to thank all LHW in the North East and Cumbria for their work, patience and understanding over the last 6 months when planning and facilitating all 21 focus groups for the Great North Care Record Project. Whatever part each member of the LHW team played along the way, each focus group ran like clockwork for the CHC and Teesside University team who were thrilled with each event. LHW made CHC's role and HWD's role so much easier than they could ever have imagined. What a magnificent team we all made across the North East and Cumbria!!

4. Feedback

a) Connecting Health Cities - Mark Walsh - Operations Director:

"The Connected Health Cities (CHC) team approached Healthwatch Darlington (HWD) with a view to holding a series of public engagement sessions across the North East and North Cumbria (NENC) in 2017. The consultation was on data and information sharing for

use in healthcare, including for planning and research purposes, and hence was a sensitive and (potentially) complex topic. HWD worked closely with us to scope how this could be done, culminating initially in three sessions in Darlington to trial the format and materials developed. This included HWD ‘coaching’ us on the audiences, their varying needs and how we had to adapt our language and materials appropriately.

Following the initial three ‘trial’ sessions we asked HWD to coordinate consultation meetings in each of the further 12 CCGs across the NENC, at least one in each area with a maximum of 40 participants per session. Our timescale was quite challenging (September to mid-December 2017) but HWD managed to achieve this, and we totalled 21 sessions in total to about 340 participants from a variety of backgrounds. Despite the logistical challenges (participant packs bespoke to each locality, facilitated discussions, equipment for audio, video and presentation material) we couldn’t have envisaged the sessions going any better, and the level of participation and feedback received was invaluable in shaping our onward programme. To turn-up to each session with everything ready and the public participants fully informed was way beyond our expectations!

At all times HWD were very professional, extremely well organised and had great knowledge of the needs and expectations of the people we wanted to engage with, and how to do this successfully. We look forward to collaborating with HWD and the wider Healthwatch network going forward.”

b) Local Healthwatch:

1. How satisfied were you with the information and documentation provided by Healthwatch Darlington for the GNCR Focus Groups?

90% Very satisfied 10% Satisfied

- *“Very comprehensive and useful, also ensured consistency”*
- *“Very comprehensive and made delivering the sessions very easy. All we needed to do was get bums on seats!”*

2. How satisfied were you with the GNCR focus groups and events you delivered?

33% Very Satisfied 67% Satisfied

- *“We had a good cross-section of people attending, all of whom participated and found the event worthwhile”*
- *“Feel at least on face to face meeting with Joe and his team before the process started might have been better as questions could have been answered ahead of time and greater awareness of expectations achieved as a consequence. The team arrived on the day and started presentations immediately so there was no opportunity to discuss anything then”*
- *“We enjoyed the sessions and giving people the chance to share their views. The funding allowed us to provide lunch which was really appreciated by people. Slightly disappointed in Teesside Uni’s facilitation as had to intervene to ensure all participants had the chance to contribute as the open questions to the whole group allowed stronger voices to dominate”*
- *“It was quite difficult to encourage people to initially engage in the events as many did not understand or were not aware of the GNCR”*

3. Overall, how effective were Healthwatch Darlington in communicating information and timelines to you?

78% Extremely Effective 22% Very Effective

- *“Communication was excellent!”*
- *“HW Darlington communicated clearly and effectively and were there to answer queries”*
- *“Very effective and also very helpful in chasing up any outcomes for us to share with participants. The most important bit!”*
- *“Very informative and kept us abreast of all updates”*

4. Would you be happy to work on a regional project with your Local Healthwatch colleagues again?

100% Yes 0% No

- “Information, support, advice, guidance and patience from HWD was brilliant thank you. I wouldn't have been so confident running such a successful event were it not for the support and co-ordination from HWD. THANK YOU”
- “Certainly, very much the way we need to work in the future to have greatest involvement for the public benefit”
- “Absolutely but would prefer face to face contact at the commencement of any project and the opportunity to input”
- “I think we need to work together to deliver impact. I don't think this project would have worked without Darlington coordinating. It was crucial to have a lead as poor Michelle had to do a lot of chasing to ensure everyone booked in focus groups and a lot of liaising between us and CHC.

5. Next Steps

- HWD has ensured that the CHC team have produced a thank you letter for all attendees of the LHW focus groups and events to ensure participants feel appreciated, and to acknowledge their involvement in shaping the Great North Care Record concept. This was cascaded to all LHW in March.
- Discussions are planned in April regarding the ongoing engagement of the public with the GNCR project such as the potential regional Patient Reference Group/Citizens' Jury to include a nominated person from each locality who attended one of the focus groups.
- The results of the regional engagement and how this is being used in shaping the GNCR and influencing the decision making process, is due to be published by the CHC and Teesside University team in April. This will be cascaded to all LHW and focus group participants.

Contact:

Michelle Thompson BEM
Chief Executive Officer

Healthwatch Darlington Limited; Jubilee House, 1 Chancery Lane, Darlington, DL1 5QP

Mobile: 07877 673030 Tel: 01325 380145

Email: m.thompson@healthwatchdarlington.co.uk