

#thewholeme



‘The whole me’

Conference 2017

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Introduction

As of 1 April 2017 Healthwatch Newcastle and Healthwatch Gateshead have both been run by the same organisation, Tell Us North CIC. This provides a great opportunity to combine resources and work together for the communities of Newcastle and Gateshead.

On 5 April 2017, the first combined Healthwatch Newcastle and Healthwatch Gateshead conference took place at The Beacon, Westgate Road, Newcastle upon Tyne.

This year's conference theme was 'The whole me', emphasising the need for the organisations who plan, buy and provide to look beyond someone's immediate situation and tailor their care to people's individual needs. This includes consideration of people's wider needs, responsibilities and lifestyle.

The event was attended by over eighty delegates including members of the public and representatives from the voluntary and community sector, public sector and commercial organisations.

The conference was opened by Kate Israel, Chair of Healthwatch Newcastle and interim Chair of Healthwatch Gateshead, who welcomed everyone. Kate explained about the new closer relationship between Healthwatch Newcastle and Healthwatch Gateshead saying that both local Healthwatch will remain separate entities, with their own dedicated offices and setting their agenda based on their local needs. Each will have their own independent Committee to oversee their work. There will be opportunities to combine research efforts across Newcastle and Gateshead where this makes sense and for each Healthwatch to work on their own local issues if this is the best approach. Kate advised that Healthwatch Gateshead was recruiting members for the Committee, which holds the executive of Healthwatch Gateshead to account. Anyone interested in the role was encouraged to apply.

Kate explained these were challenging and uncertain times with less money available for public services and reports that NHS staff morale is low. Kate said that this time of strain on public services made our work at Healthwatch even more important.

Steph Edusei, joint Chief Executive of Healthwatch Newcastle and Healthwatch Gateshead, then spoke frankly about her own health over the past year and her experiences of the NHS services. She received great care and everything had been fully explained to her. However, Steph said that staff didn't take the time to find out about her wider interests, responsibilities and needs ('the whole me'), and that these are important factors in an individual's recovery and the ability to be 'well'.



The conference agenda

Spotlight on SEND

Presented by Luke Arend, Project Manager at Healthwatch Newcastle

Our work in Gateshead over the past year

Presented by Victoria Clark, Signposting and Information Officer at Healthwatch Gateshead

Healthwatch Newcastle and Healthwatch Gateshead priorities for 2017–18

Led by Steph Edusei, Chief Executive of Healthwatch Newcastle and Healthwatch Gateshead

Care homes research ‘My home my say’

Presented by Lyndsay Yarde, Project manager at Healthwatch Newcastle

Keynote speaker – Tommy Whitelaw

Dementia Carer Voices Project

Spotlight on SEND

The experiences of and services for children and young people with special educational needs and/or disability (SEND) was a research priority during 2016–17. Project Manager Luke Arend gave a presentation on the work carried out, our findings and impact the work has had so far.

In 2014 the government set out reforms in SEND provision that aimed to improve the support provided to children and young people with SEND. The three main aims of the reforms are:

1. Providers to work closer together
2. Parents and service users to have more say
3. Service users to be more empowered

We believed that, as the implementation of these reforms had been running for two years, it was an opportune time for us to systematically gather service user views and provide evidence for ongoing improvements to these new and potentially transformative ways of working.

We aimed to gather service users’ experiences of SEND services for those with a high level of need of SEND services (i.e. those with a Statement or Education, Health and Care plan), with a special focus on the new assessment and planning tools which are part of the SEND reforms.



We carried out four focus groups and a series of interviews with SEND stakeholders that were a very rich source of themes and issues. Two questionnaires were also developed, which went out to parents/carers and to young people with SEND (16–25 years). We received a very good response to these, from more than 200 parents and carers and more than 50 young people (1 out of 7).

We found that most people were satisfied with the support they received. Feedback on the impact of having a statement or plan was very positive. Most respondents saw an improvement moving from the old system to the new system.

However, service users raised a number of challenges and concerns. The key ones were:

1. Communication – people felt it was important to have a good dialogue with the service provider and improvements were needed.
2. Who's who – many parents and carers were unaware of who does what and where to go for support; others had very little or no knowledge of the reforms.
3. Preparing for adulthood was a main concern and parents did not think that the Education, Health and Care plans sufficiently addressed these concerns. Young people told us that they would most like extra support in preparing for adulthood by being taught life skills. Parent/carers also felt life skills were very important.

Parents and carers were most satisfied with hospital care, social workers and GPs, and least satisfied with mental health services and 'Get Connected' social activities provision.

Twelve recommendations were made. The key four key recommendations were:

1. To provide a single point of contact for parents/carers/service users and for parents/carers/service users to have more say in what support the child receives (the SEND code of practice – <http://tinyurl.com/omv3tpc> – recommends there is a single point of contact).
2. To provide more information on who does what, and more information about the SEND reforms.
3. Preparing for adulthood to be made a priority.
4. Invest in life skills training for young people with SEND.

Luke told delegates that Newcastle City Council, which was leading on SEND reforms, had been very supportive throughout this work. It is now working on an action plan based on the recommendations in the report. Although the report was published less than a month before the conference (March 2017) a number of recommendations had already been agreed. Development of a single point of contact, a 'who's who' guide and frequently asked questions (FAQs) have been committed to, and a proposal made for a conference for schools on life skills training and preparation for adulthood.

Luke said there were real challenges to ensuring that service users have personalised SEND care in Newcastle: because there are many SEND service providers it is complex for service users to understand as well as providers themselves; there are also resources challenges,

with demand exceeding provision in some cases. However, he suggested that the aims of the reforms and Newcastle City Council's enthusiastic and speedy action on this feedback from service users, showed there is reason to be optimistic about SEND services being tailored for the individual in future.

Read the SEND report at <http://tinyurl.com/gomnrhe>

Our work in Gateshead over the past year



Victoria introduced the Healthwatch Gateshead staff and volunteers at the conference. Healthwatch Gateshead had been working over the last year to give a stronger voice to residents of Gateshead.

Three key areas of work over the past 12 months were highlighted:

1. Enter and View at Teams Medical Practice

Victoria explained the Enter and View process and aims. This Enter and View looked at “meaningful patient engagement” within a GP setting that complimented the criteria of the Care Quality Commission inspections.

The report and findings were shared with the Practice, Care Quality Commission, Newcastle Gateshead Clinical Commissioning Group (CCG) and other stakeholders. The CCG received our report favourably and it has been shared with all other GP surgeries within the borough as a good practice guide to encouraging meaningful patient engagement.

Read the report at <http://tinyurl.com/yaanedwp>

2. Healthwatch Gateshead annual event

Members of the public were invited to talk face to face with decision makers from key health and social care agencies. This included all the key local organisations: Northumberland Tyne and Wear NHS Foundation Trust (NTW), Gateshead Healthcare NHS Foundation Trust (Queen Elizabeth Hospital), Newcastle Gateshead CCG, North East Ambulance NHS Foundation Trust (NEAS), Public Health and Social Care from Gateshead Council and CCG-funded Health Champions.

Recommendations from the event included:

- NTW to develop a single point of contact for Gateshead residents
- Newcastle Gateshead CCG to develop clean and simple guides for NHS Continuing Health Care pathways for both adults and children
- NEAS to consider the need for accessible transport for wheelchair users when going to hospital for treatment
- Public Health to better inform members of the public how to access information to support their own health needs

- Adult Social Care to improve the process of accessing social care reviews and assessments for residents
- Newcastle Gateshead CCG to publicise Health Champions alongside the social prescribing agenda

We are currently asking these organisations for an update on the actions they have taken following the event.

Read the annual event report at <http://tinyurl.com/y8uzlln6>

3. Mystery shopping exercise

We carried out a mystery shopping exercise to find out how much frontline staff knew about the Accessible Information Standard legislation.

This work was prioritised because of feedback from the annual event which showed that people with hearing impairments continued to face challenges when accessing services despite Accessible Standard Legislation being in place.

The Accessible Information Standard is applicable to all publicly-funded adult services in England, including GP practices, dentist and opticians. NHS England states “The standard aims to make sure people who have a disability, impairment or sensory loss are provided with information they can easily read, or understand with support, so they can communicate effectively with Health and Social Care services.” The Standard places a responsibility on providers to identify, record, flag, share and meet the information and communication support needs of patients where those needs relate to a disability, impairment or sensory loss.

Ten GP practices, six opticians and six dental practices were randomly selected. Volunteers then contacted these services asking specific questions about communication support for people who have a hearing impairment when contacting the provider, during appointments and how they could be involved with the practice.

The key findings were:

- Almost all of the staff we spoke to were unaware of their legal responsibility under this legislation to identify, record and meet the additional support needs of patients
- The support offered by some of the providers did not appear to promote independence and actually encouraged dependence on family members

The findings were shared with Newcastle Gateshead CCG and the report was received extremely favourably. The CCG has shared the report with GP and dental practice managers with a view to improving services in the future.

Read the report at <http://tinyurl.com/y9cvkh33>

Following Victoria's presentation, Steph explained that Healthwatch Gateshead and Healthwatch Newcastle will continue to run from two offices but function under one umbrella, giving the opportunity for joint events when of mutual benefit, as well as individual events where more appropriate.

Healthwatch Newcastle and Healthwatch Gateshead priorities for 2017–18

Steph began by explaining that we set priorities each year from a shortlist, drawn up by our Committees and informed by service user feedback, data analysis and our understanding of what is of current significance at both local and national levels. We ask people to prioritise the issues on the shortlist at community events, online and at the conference. Our Committees then decide on the final list of priorities for the coming year based on these views.

The priorities shortlist for Newcastle was:

1. Mental health
2. Cervical and breast cancer screening and vaccination programmes
3. Health and care services for care leavers and young homeless people
4. Podiatry services
5. NHS continuing healthcare funding/reimbursement

The priorities shortlist for Gateshead was:

1. Black and Minority Ethnic (BME) health needs
2. Carers
3. End of life care
4. GP services
5. Mental health
6. Social care
7. Queen Elizabeth Hospital
8. Young people

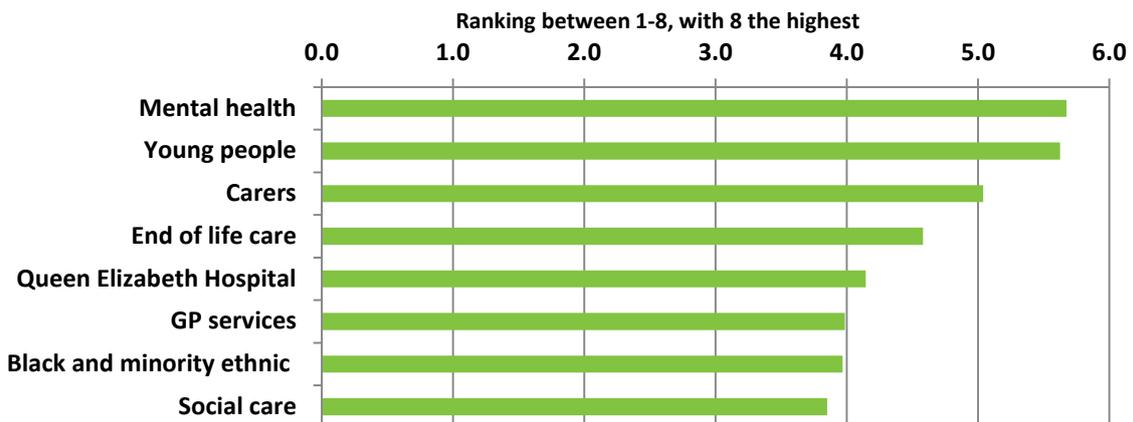


At the conference, each was asked to decide which of the shortlisted priorities they would take off the list if forced to do so – what would they would ‘throw out of the hot air balloon?’ This allowed people to discuss and debate what they considered to be high or low priorities.

Participants were then asked to rank the priorities for both Newcastle and Gateshead. The graphs below show the results, with the most popular choices at the top.

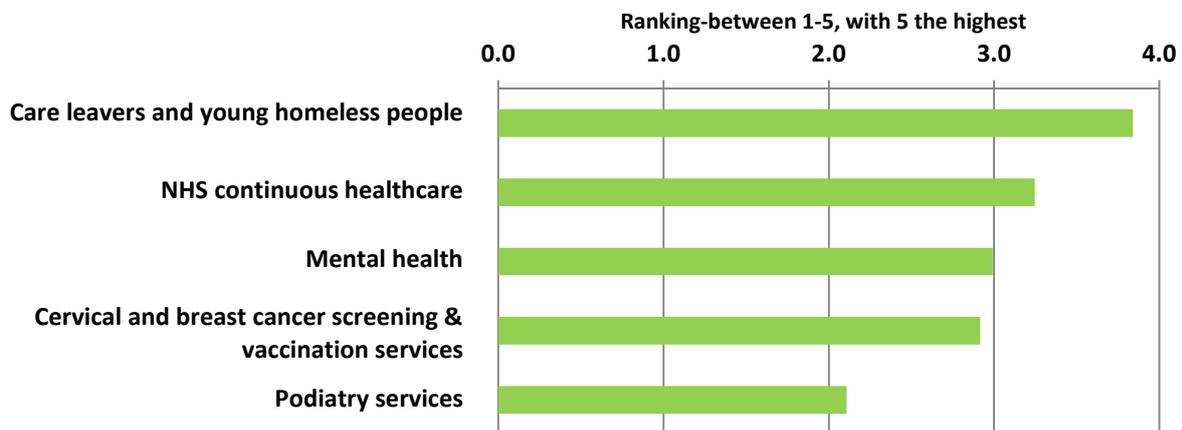
Healthwatch Gateshead: Ranking of 2017-18 priorities from conference and online/community vote

Total votes:
136



Healthwatch Newcastle: Ranking of 2017-18 priorities from conference and online/community vote

Total votes:
122



Next steps

The prioritisation results were discussed by the Healthwatch Newcastle Committee and our priorities for Newcastle for the coming year are:

1. Social and health services for care leavers and young homeless people
2. Continuing Health care
3. Cervical and breast cancer screening and vaccination services
4. Mental health services

The interim Healthwatch Gateshead Committee discussed the prioritisation results and decided that the 2017–18 priorities for Gateshead are:

1. Carers
2. Continuing healthcare
3. Mental health services

Care home research: 'My home my say'

Lyndsay Yarde explained that Healthwatch Newcastle had carried out research into how care homes involve their residents and their relatives in the care they receive and how they are involved in the running of the care home.

Involvement was chosen as a focus for this work because there is a legal requirement to involve under the Care Act 2014 and it is mentioned in guidance from both the Care Quality Commission (CQC) and NICE. It is also known to be a good indicator of quality. However, 'Better care in my hands: A review of how people are involved in their care' (CQC, 2016) found that those over the age of 75 were among those who felt least involved in the care they received.

There are many benefits in involving care home residents, not only for residents but also for their relatives and the care home providers. Benefits include improved cognitive functioning and emotional wellbeing for residents, increased knowledge and understanding for relatives and improved satisfaction levels for providers.

Lyndsay told us that during the summer and autumn of 2016 copies of three surveys (one for care home residents, one for their relatives, and one for care home managers) were circulated to all 47 of the city's care homes for older people. In addition to the surveys, Healthwatch staff and volunteers visited ten homes to gather further views and information.

The resulting 'My home, my say' report collated the views of more than 150 care home residents, relatives and managers, as well as our own observations. It also highlighted the many examples of good practice we found across the city and included three case studies of particularly innovative examples of involvement. The main findings of the report were:

1. General satisfaction levels in care homes were high
2. Most people felt fully or somewhat involved in their care
3. Residents felt slightly more involved than relatives
4. A significant minority wanted to be more involved

The three recommendations of the report are for care homes to:

1. Develop an organisational culture which believes that involvement is both valuable and viable
2. Put in place policies and procedures that ensure that involvement happens as a matter of course
3. Provide staff with the skills, training and time to enable them to involve all residents in ways that work for them

Lyndsay explained that all of Newcastle's care homes have now received the report, as have commissioners and those who monitor services. The next step is to follow up the report to ensure it has an impact.

Read the report at <http://tinyurl.com/zfnsskj>

Keynote speaker – Tommy Whitelaw

Tommy passionately and emotively shared with us his experience as a full time carer for his mother from 2007 to 2012, who had vascular dementia. Tommy emphasised how language was critical in what we do. He started his journey by writing a blog to find out how other people managed as carers, hoping it may help him.



Now Tommy gives talks around the UK as part of the 'You Can Make a Difference' campaign. The Dementia Carer Voices group has been a huge success and is now funded by the Scottish government.

Tommy had felt helpless and alone until a district nurse offered her support and listened to him, taking the time to find out more about his mother. The help from the nurse was profoundly powerful, at a time when he needed it most.

Tommy told delegates that just over 13,000 individuals from hospitals and universities, nurses and students had pledged what they will do to make a difference. He added that 6 June was the 'what matters to you' day (#wmt17) where people would be encouraged to look at ten things important to the person they cared for.



A delegate noted that staff were under such time pressure to get to the next patient that the individual can get forgotten. Tommy replied that we need to reevaluate what time means and understand the feeling of isolation that people feel. Loneliness is a common theme and we can help to change that. Tommy advised the database of pledges would be published at the end of April.

Steph thanked Tommy for his openness and honesty, encouraging people to make their pledge and said that Tommy's slides would be shared.

Conference feedback

All the speakers were excellent

Excellent conference – so emotional!

Very inspiring talk from the keynote speaker Tommy

Overall, feedback on the conference was very positive. Words such as ‘fantastic’, ‘high quality’ and ‘well organised’ were used to describe the event.



A number of people found the presentations by Tommy and Steph inspiring, emotive and impactful.

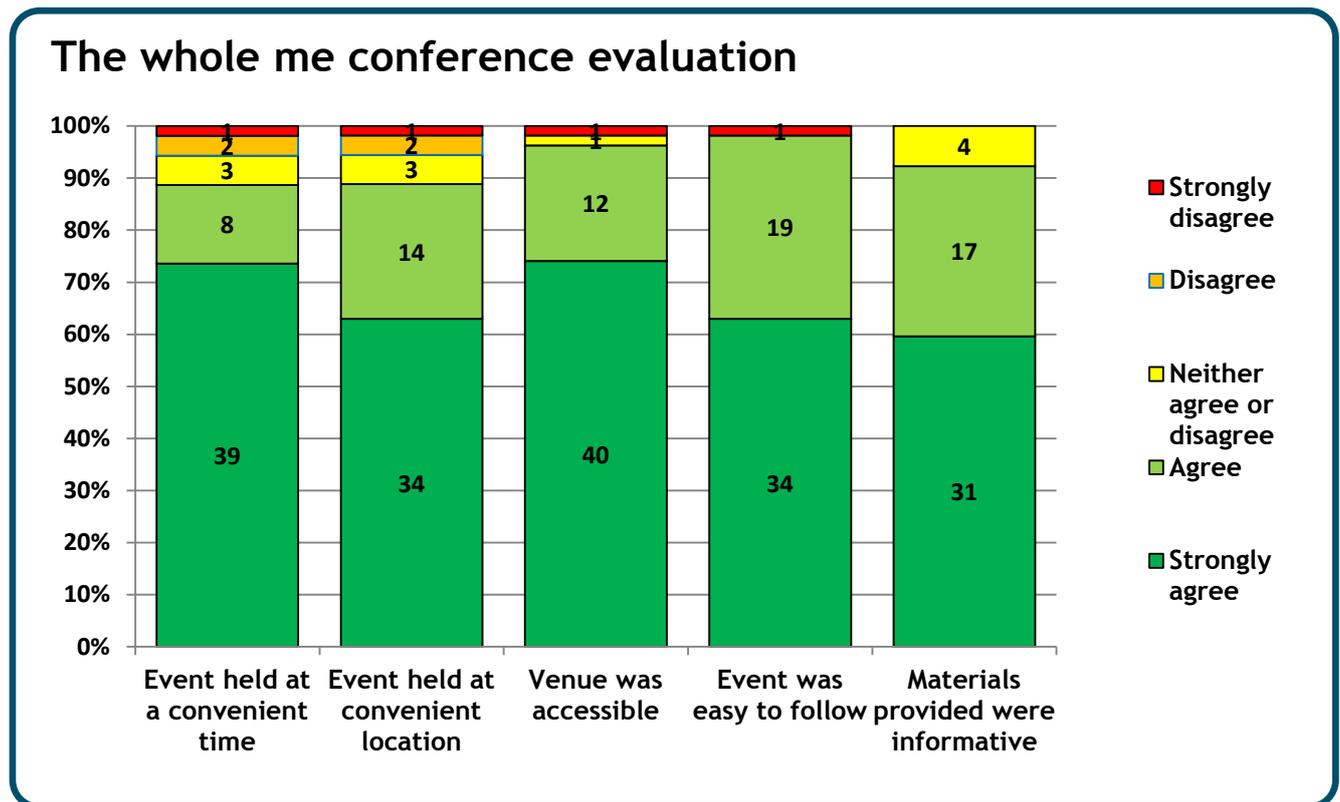
We received good feedback about the priority-setting session, and there were appreciative comments about being able to have a say in choosing our priorities for the coming year.

Respondents made other suggestions including starting later so retirees can use the free bus service and providing information on bus times and routes. The previous year’s conference began and ended at a later time but unfortunately we found that many attendees had to leave early. The conference evaluation showed that people were generally very satisfied with the location and timing of the conference and found the event easy to follow and the materials informative. In response to last year’s feedback, we decided to have a morning only event this year.

Fantastic event – thank you!

Usual excellent organisation

The graph below gives an overall view of the evaluation.



As usual, all of this feedback will be digested and used to inform our planning for future events including next year's conference.

Contact us



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