Event report

West of England Learning Disabilities Collaborative Launch Event
24 April 2019, Bristol Pavilion

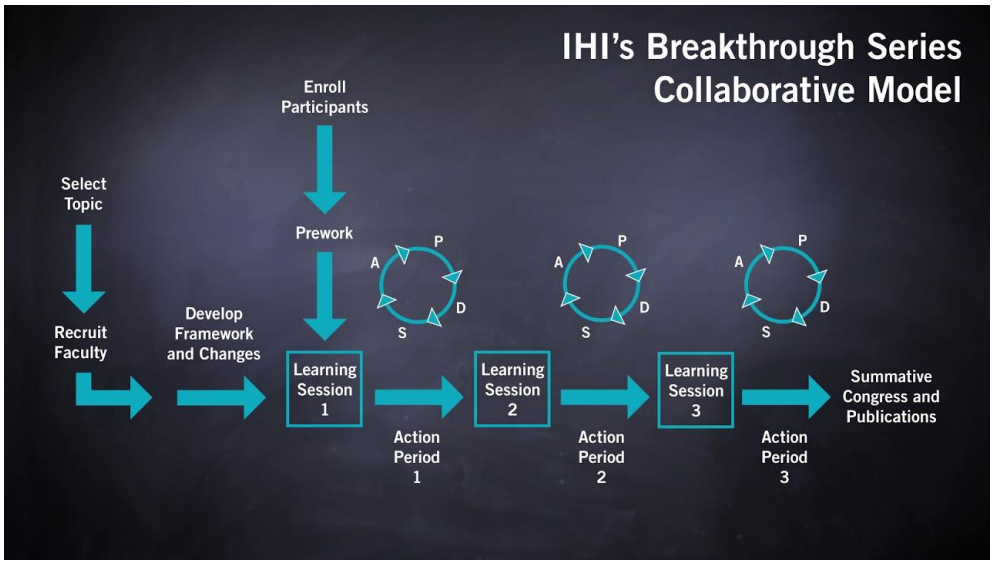
All main presentations can be found here
Click here for an easy-read guide to the West of England Academic Health Science Network

Introduction

On 24 April 2019 the first event to launch the West of England Learning Disabilities Collaborative was held at the Bristol Pavilion. This collaborative is co-led by the West of England Academic Health Science Network (AHSN) and Kevin Elliott from NHS England and Improvement. Kevin is the Lead Nurse for the South West Learning Disability Programme. 130 people attended the event. The day had a mix of plenary presentations and discussion workshops.

The event aimed to bring together passionate people interested in improving health outcomes for people with learning disabilities. The objectives were to give people the opportunity to find out about exciting things happening both locally and nationally, as well as the space to get involved with this work through the workshops. It was also to launch the collaborative, giving people the opportunity to meet and share ideas and good practice with others.

Whilst this project started as a small group of interested people wanting to work together, there has been more enthusiasm than we could ever have anticipated. Fortunately, the West of England AHSN has lots of experience hosting collaboratives using the Institute of Healthcare Improvement's (IHI) Breakthrough Series Collaborative Model. This model was used to help spread the National Early Warning Score across our health system, as part of our Deteriorating Patient programme. The NHS Patient Safety Measurement Unit has shown that this work has helped the West of England to achieve the lowest rates of mortality from Suspicion of Sepsis in England. This model works at a regional level, and it is exciting to consider how it can be applied to help improve health outcomes and reduce mortality in people with learning disabilities. It was highlighted at the event that members of our project steering and advisory groups are all collaborative members: every individual has the power to lead and make change, no matter how big or small. Looking at the image below from the IHI, this launch event would be 'Learning Session 1'.



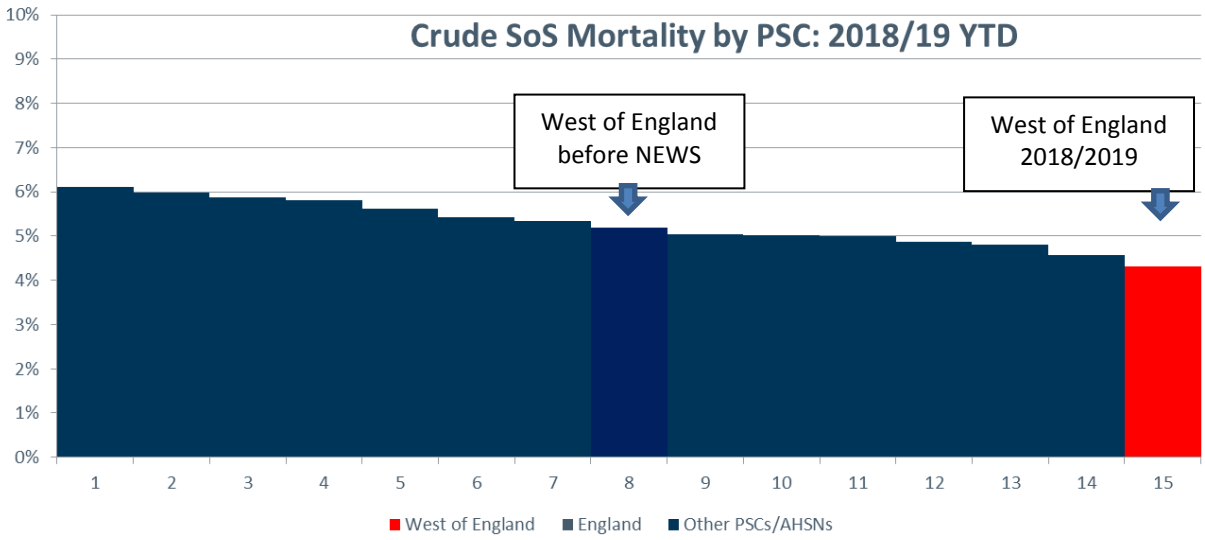
To give the opportunity to continue conversations after the event, we created a West of England Learning Disabilities hive on our free online platform: hyvr (have your vision realised). This space is for anyone in the West of England with an interest in this regional approach to collaboration.

One thing that really stood out was the range of different people, from many different backgrounds, that came and contributed at the event, including:

What speakers said

Welcome from Anne Pullyblank (Medical Director, West of England Academic Health Science Network)

Anne welcomed everybody, including the helpful Jargon Busters on each table. Anne introduced, in a nutshell, what the West of England AHSN does and thanked Kevin Elliott from NHS England and Improvement for co-leading this work with us. Anne outlined what a collaborative is, and described how it has helped us achieve success in reducing mortality from Suspicion of Sepsis (SoS) with the National Early Warning Score (NEWS).



Anne suggested that in order to achieve the aim 'reduce premature mortality and improve health outcomes for people with learning disabilities' in a manageable way, it is wise for the collaborative to have a defined initial focus. The three things for our initial focus are to:

- Facilitate appropriate use of NEWS2 and soft-signs deterioration tools
- Increase the frequency, and standardise the quality, of annual GP health checks
- Increase uptake of flu vaccination

Anne gave apologies for Ray James and Aaron Oxford, who unfortunately were unable to attend due to illness. The slides for the presentation they had planned can be found here.

NEWS2, annual health checks, flu vaccination, Alison Tavaré, Primary Care Clinical Lead, West of England AHSN, Kevin Elliott, Lead Nurse: Learning Disability Programme, NHS England and Improvement and Beth Sage (Expert-by-Experience)

Alison opened this session by introducing the National Early Warning Score (now NEWS2) and demonstrating how easy it can be on Hannah from the West of England AHSN.

Alison Tavaré outlined our cross-system success with NEWS2 and referenced a fabulous video, Paul's Story which shows the lifesaving benefits of NEWS2 through the journey of a patient, from his GP to an ambulance and into hospital. Alison then shared the experience of her nephew, Toby, who has profound and multiple learning disabilities, with the audience, and informed us that Toby inspired her to want to lead this work. Toby had his NEWS score

calculated by his mum and it helped him to get the urgent treatment he needed in hospital when he became unwell with an infection.

Kevin Elliott and Beth Sage then came to the stage, presenting together. Kevin began with some stark and very important facts:

> The average age of death for people with a learning disability is 65 for men and 63 for women, compared to 78 for men and 83 for women in the general population.

> 37% of people with a learning disability die from avoidable causes, compared to 8.8% of the general population.

Kevin outlined the many ways in which an annual health check can help to reduce health inequalities. They are a great opportunity to address individual health and wellbeing concerns and to provide person-centred healthy lifestyle guidance. However, many opportunities are being missed, as only 52% of adults with a learning disability on the GP or health register in England receive an annual health check. Kevin highlighted that an evidence review from Public Health England found that health checks improve the early identification of health problems, including serious and life threatening conditions such as cancer, heart disease and diabetes. They allow healthcare professionals to take targeted actions, with the individual, to address these needs.

Kevin and Beth finished off their presentation by inviting Beth Richards and Dan Bryan from the Misfits theatre company up to the stage. Beth Richards emphasized that “health is everybody’s responsibility”, and Dan hammered this home to members of the audience with the statement “that means you”. The audience broke into a well-deserved round of applause. Annual health checks are something the Misfits know a lot about. Click here to see their fantastic video about them: ‘Health is Everybody’s Responsibility’.

Following this, Alison and Kevin invited Helen Ballinger from Gloucestershire CCG to share the great work they are doing using telehealth and NEWS2, including in care homes for people with learning disabilities. Telehealth can support individuals with long term conditions to "own their condition". It can involve taking observations, which are uploaded to a platform which flags when something isn't quite right. This has the additional benefits of providing baseline vital signs data for people and also can help those who use it regularly to become desensitized to things such as having their observations taken. They showed a fantastic video, from their CCG channel, outlining the work in more detail, which concludes with a patient describing that Telehealth gives her "peace of mind in the home":

hyvr (Have **Y**our **V**ision **R**ealised**), Jo Bangoura, West of England AHSN**

Jo introduced the free online platform hyvr, outlining ways it can be used to continue collaborative conversations after the event. It has been created by the West of England AHSN, which means it's free to use, no spam, no catches. It is an open space for people in the West of England to work together regionally. To join the conversation, sign up at www.hyvr.co.uk and search for (and follow) the West of England Learning Disabilities Collaborative hive.

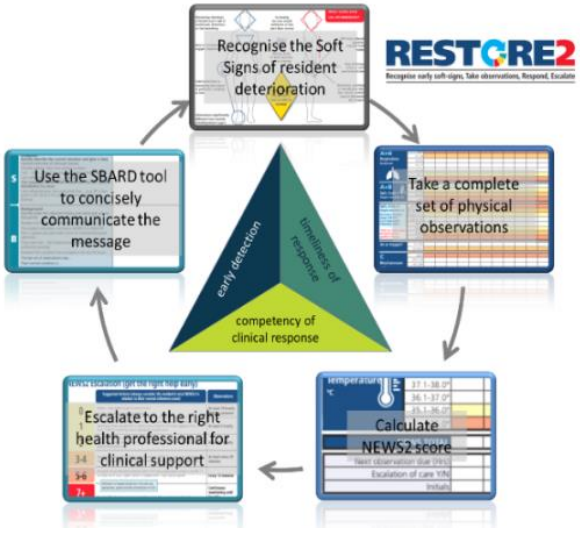
Keynote 2: RESTORE2 (Recognise Early Soft-Signs, Take Observations, Respond, Escalate), Mathew Richardson, Deputy Director of Quality, NHS West Hampshire CCG

Matthew introduced RESTORE2, developed by West Hampshire CCG, as providing the tools for common language across healthcare. RESTORE2 is a bundle containing:

- A soft-signs of deterioration early identification tool
- NEWS2
- The structured communication tool SBARD (Situation, Background, Assessment, Recommendation, Decision)
- Prompt to consider the ReSPECT process, if appropriate

The purpose of these tools is to help with the early identification, timeliness and competence of clinical response to physical deterioration. It is free for anyone to use and comes complete with training package. For more information, visit www.westhampshireccg.nhs.uk/restore-2.

West Hampshire CCG have used RESTORE2 extensively in care homes to safeguard residents from the risks of unidentified deterioration. Matthew highlighted the importance of not hospitalising people's homes. Rather than introducing regular observations to care homes, the soft-signs tool can act as a prompt for when to measure a person's NEWS2 score. If someone is showing soft-signs of being unwell, such as being shivery, feverish, hot or clammy, or being off their food, working out their National Early Warning Score and escalating the concerns using a structured communication tool could keep the person safe. It could enable them to get a timely response from an appropriate clinician, for prompt curative or palliative (or both) treatment, depending upon the person's pre-documented wishes. RESTORE2 encourages carers to consider what a person would like if they become unwell, what is normal for them physiologically, and when to seek help. Many carers have reported that it empowers them to recognise and escalate when they have concerns.



Matthew also showed that RESTORE2 has resulted in a significant reduction in ambulance conveyances of people to hospital, which suggests that it is helping to identify the people who are really ill and in need of help, and not take people to hospital unnecessarily, which we know can be harmful.

Matthew's key messages were:

- Soft-signs can provide a prompt for appropriate use of NEWS in the community
- Soft-signs are not specific enough to be used alone as a trigger for medical review
- A structured communication tool supports effective communication
- RESTORE2 can get people the help they need in a timely way
- West Hampshire CCG are seeing a significant reduction in unnecessary hospital admissions, and shorter length of stay for others due to early intervention. This is saving lives.
- Outcomes are dependent on leadership, relationships with primary care services and anticipatory care planning.
- The team are working to adapt the tool so that it can be used to support people with learning disabilities – this was the focus of Matthew's workshops (see below).

Keynote 3: LeDeR (Learning Disabilities Mortality Review), Pauline Heslop, Professor of Intellectual Disabilities Research, University of Bristol

Pauline made a very strong case for the importance of mortality reviews for people with learning disabilities. In 2018, LeDeR found that men with learning disabilities die 23 years sooner than average, and women with learning disabilities die 29 years sooner than average. The LeDeR programme aims to:

- Support improvements in the quality of health and social care service delivery for people with learning disabilities
- Help reduce early deaths and health inequalities for people with learning disabilities.

LeDeR achieves this by supporting local reviews of deaths of people with learning disabilities. Since the programme started LeDeR has been told about the deaths of over 4,000 people, and has reviewed over a quarter of these. The government response to the 2016/17 LeDeR report, published in September 2018 agreed to 24 actions in response to recommendations. Read the response here.

Pauline celebrated the fact that the NHS Long Term Plan supports the continuation of LeDeR. Find out more about this vital programme.

Pauline invited Emily Handley-Cole, who is the NHS England Premature Mortality Governance & Development Lead, and also London Regional Coordinator for the Learning Disability Mortality Review (LeDeR) Programme, to outline her work with the LeDeR Learning Into Action programme. The Learning Into Action programme helps to translate LeDeR findings into local and national improvements. They also host a national forum for healthcare professionals. To join this online network, email: england.ldmortalitynetwork@nhs.net .

Next steps / Ideas into action / SMART pledge share (Kay Haughton, Director of Service and System Transformation and Kevin Hunter, Head of Patient Safety and Programme Delivery, West of England AHSN)

Following a brief opportunity for workshop hosts and facilitators to feedback highlights from their workshops, Kay opened the 'next steps' session with an inspirational statement: "in this kind of collaborative work, everyone counts: whatever small thing you pledge to do today, feel empowered to go off and do it." Kay picked up on the infectious enthusiasm in the room, which many people had commented on throughout the day.

Delegates were then invited to finish off their pledge cards, which had space to write a personal pledge following each of the workshops they attended. These were briefly discussed on tables and collected in by facilitators.

There are so many inspiring pledges, many of which have already been turned into action. We pledge to post these back to delegates, during the month of June, to keep as a reminder of the day. Turning pledges into action are next steps that everyone who attended can help with.

The next step for Kevin, Alison and Hannah is to meet with local commissioners from across the West of England to establish how we can support each other to make systemic improvements.

For members of the steering group, advisory group (now known as 'the collaborative') and anyone else from in area who is interested in the West of England, hyvr provides a space to collaborate, share ideas and initiatives.

Workshop Reports

Special thanks to workshop facilitators for helping with these

RESTORE2 Workshop

Hosted by Matthew Richardson, NHS West Hampshire CCG
Facilitated by Hein Le Roux, West of England AHSN



Highlights:

- Enthusiasm from family carers
- Opportunity to focus on soft-signs of physical deterioration

Contrast between sessions:

- The first workshop had more family carers and focused more on how the tool might work for them in the home. There was a strong view from them that many people with learning disabilities live at home and often have a relation who is caring for them, rather than a professional carer. It was important that the RESTORE2 tool was able to meet their needs.
- The second session was mostly attended by clinicians, who spent time discussing the subtleties of the soft-signs of physical deterioration. It was concluded by many in the group that the value of RESTORE2 is its simplicity.

Next steps:

- Matthew Richardson has lots of ideas about adapting the tool for people with learning disabilities to take back to the team. RESTORE2 was originally designed with elderly people in care homes in mind.

- A draft bespoke RESTORE2 exists, and feedback from experts attending these workshops can help inform next steps for this.

What resonated?

- The passion from family carers, and the desire to use it in the home
- Mathew Richardson's thoughtful approach to adapting RESTORE2 for people with learning disabilities

Flu Workshop

Hosted by Donna Glover, Public Health England and Anna Marriott, National Development Team for Inclusion
Facilitated by Joanna Garrett, West of England AHSN



Highlights:

- Good engagement with a diverse mix of attendees
- Public Health representatives came away with new information, regarding issues and ideas

Contrast between sessions:

- The first workshop was more vocally represented by people with learning disabilities and care organisations and therefore focussed more on personal user experience and the second session was more populated by clinicians, particularly primary care and therefore there was a greater focus on system issues such as the process of patient identification
- Prior to the day the second session was planned to be significantly larger, but additional on day sign-ups on the day increased the numbers in the first session.

Next steps:

- Public Health to take learning from event back to inform work including agreed need for learning disabilities to be included in the priority groups for GP vaccinations, greater clarity regarding the ability to give nasal spray vaccinations as a reasonable adjustment and the process in having this option readily available for GPs.

What resonated?

- There was surprise at the low number of patients with learning disabilities who were not receiving a flu vaccination.
- That there is potentially a need to think outside of the box to ensure these patients are protected, e.g. a reasonable adjustment might include a travelling visit to a residential facility

Annual Health Workshop
Hosted by Kevin Elliott, NHS England & Improvement and Beth Sage, Expert by Experience
Facilitated by Millie O'Keeffe, West of England AHSN



Highlights:
- The Misfits video on annual health checks and their curtain call
- Great contributions from everyone on the tables, working together to develop ideas
- Learning about reasonable adjustments and how they are encouraged in GP practices

Contrast between sessions:
- Lots more experts by experience in the first session

Next steps:
- Kevin is collating the ideas and using them to improve services and the awareness campaign on annual health checks for people on the learning disabilities register

What resonated?
- Tended to be lots of strategic conversation from clinicians as well as some very productive ideas
- How few people attend/book their annual health check, and the amazing work that Kevin is leading to increase these numbers

QI Workshop
Hosted by Kevin Hunter and Nathalie Delaney, West of England AHSN
Facilitated by Greg Harris, West of England AHSN



Highlights:
- Interactive sessions enabled participants to actively take part
- Attendees reported that they enjoyed having a role to play in activities
- Everyone experienced hand-on training

Contrast between sessions:

- The first workshop was attended by more clinical staff. The second had more experts by experience participating
- There were approximately the same number of attendees at each workshop

Next steps:

- More in-depth QI training available to those who would like it, see the AHSN website for more information

Other:

- Places at the workshop filled up within 48 hours of advertisement

What resonated?

- There was great enthusiasm to learn QI techniques and as a result the AHSN QI Academy is scoping ways it can support people involved and engaged with learning disabilities services.

A few more pictures from the day

Stands at the event