

Communications plan

Managing deterioration for people with a learning disability in supported living environments

Background

The East and West Midlands Academic Health Science Networks (AHSNs), with the East and West Midlands Associations of Adult Social Care (ADASS), are working collaboratively to support NHS England and NHS Improvement Midlands Region in responding to the [LeDeR \(Learning Disability Mortality Review\) report](#).

The LeDeR report highlights the poor health outcomes experienced by people with learning disabilities, and the challenges they and their families and carers have in identifying signs of health deterioration early and preventing health problems.

This pilot programme will provide evidence to support national work to improve care and outcomes for people with learning disabilities who are in supported living. At the end of the pilot the aim is to recommend an existing, evidence-based product, methodology or tool that can be scaled up and rolled out nationally: a clearly defined, replicable model with a 'how to' implementation guide.

The scope of the programme is to focus on deterioration associated with infection. This will include priorities areas identified by LeDeR including:

- Sepsis
- Aspiration pneumonia
- Pneumonia
- Constipation (potentially secondary uro-sepsis)

The approach will also explore the relationship between these and the presence of comorbidities of dementia, cardiovascular disease, and cancer.

This programme will not specifically include epilepsy within scope and will not explore solutions to chronic deterioration from long-term conditions.

The work will be framed within the PIER model of deterioration management, to ensure that consideration is given to where an intervention could be most impactful:

- **Prevention:** prevent deterioration, safety culture in supported living
- **Identification:** tools already being used, digital monitoring
- **Escalation:** structured communication to escalate - received and heard
- **Response:** message has been delivered, is it now being responded to?

During the programme, the team will undertake a four-phase approach:

- **Pre-diagnostics:** agree scope of the pilot, stakeholders and develop the programme plan.
 - The participating sites are:
 - Nottingham
 - Walsall
 - Lincolnshire
 - Herefordshire
- **Diagnostics:** explore and understand the 'current state' before focusing on solutions – how care is currently delivered and where the key areas for improvement are as well as examples of good practice.
 - Mapping – map supported living providers across the East Midlands using CQC registration data.
 - Intelligence gathering – develop connections and a list of key contacts through attendance at related meetings / forums and communication cascades across the systems.
- **Testing and measuring**
 - Identification of 'test sites' – The team will agree which sites will test interventions/innovations for testing from October 2021 to January 2022.
- **Evaluating and reporting**

Communications objectives

Overall pilot programme outcome

To test theories and possible mitigating tools/processes for the avoidable death of people with learning disabilities in supported living.

Success factors:

- Number of people with a learning disability in supported living settings involved in the pilot.
- Number of priority stakeholders involved in the pilot.
- Response rate to surveys on managing deterioration.

- Learning report with recommendations published and shared with key national stakeholders.

Communication outputs (communications activity)

100% of priority stakeholders reached by a mix of pilot communications and involvement channels and activities.

At least one key representative of the following, in each of the four pilot areas:

- CCG
- Local authority
- Two supported living providers
- One GP practice

Communication outtakes (stakeholder experience of communications)

Qualitative measure: evidence that at least 70% of priority audiences report being positively informed and involved in the work.

- Response rate to surveys and semi-structured interviews on managing deterioration.
- Number of people with a learning disability in supported living settings reached through the pilot (currently 91/160 target).
- Positive feedback received: quotes, testimonials, involvement in case studies - at least two from each pilot area.

Communications outcomes (measurable behaviour change)

Qualitative measure: evidence that at least 50% of priority audiences commit to continue/implement the practices and methodologies identified for managing deterioration from the pilot.

- Short 'exit survey' of priority stakeholders to understand future commitment to the pilot's aims.
- Number of key national stakeholders reached with the learning report (e.g. NHSE&I, ADASS, policy groups, advocate groups, politicians).

Principles

This is a pilot and needs focused, light-touch comms focused on delivering the pilot, rather than engaging wider stakeholders and the public.

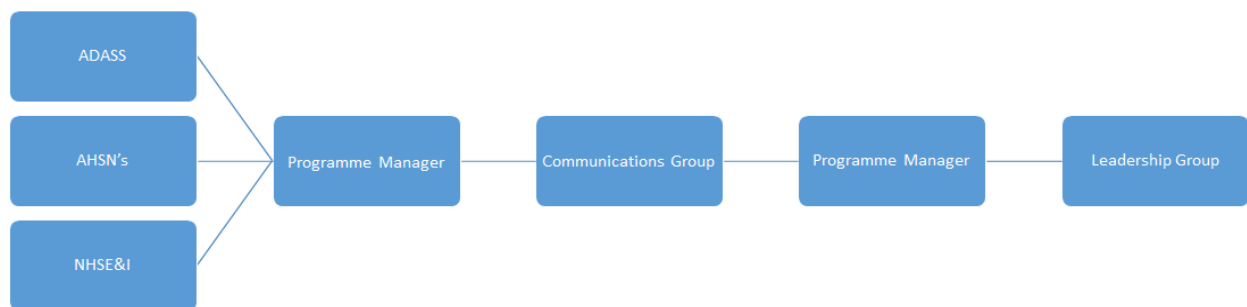
The main audiences are therefore system-based, however it is important to ensure all messages use plain language and add clarity about the pilot, the need for it, and what we hope will change, if successful.

Roles and responsibilities

The partners will collaborate on the development and delivery of this joint communications and engagement plan. Governance will be provided through the leadership group (as shown in the diagram below) and commissioning leads at NHS England and NHS Improvement Midlands Region.

All internal and external communications must be agreed by all partners in advance.

The comms leads will link with relevant comms teams in their field.



Organisation	Comms lead	Approval
NHS E&I (Midlands)	Fiona Ireson (Senior Communications Manager - Midlands) fiona.ireson@nhs.net	Roxanna Modiri roxanna.modiri2@nhs.net
East Midlands AHSN	Bernard Allen (contractor) bernard@bernardallen.com	Samson Ifere (Programme Manager) samson.ifere@nottingham.ac.uk
West Midlands AHSN	Represented by Bernard Allen	Leadership group
East Midlands ADASS	Paul Masterman supporting	Leadership group

West Midlands ADASS	Paul Masterman (communications associate and consultant) paul.masterman@blueyonder.co.uk	Leadership group
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Meetings

Comms leads will meet regularly throughout the programme, as appropriate.

The programme leadership group meets every 6-8 weeks; Samson Ifere represents communications on the group.

Key messages

What

Care and health professionals in the Midlands are working together on better ways to prevent the premature and avoidable deaths of people with learning disabilities.

The East and West Midlands Academic Health Science Networks (AHSNs), with the East and West Midlands Associations of Adult Social Care (ADASS), are working collaboratively on a pilot programme commissioned by NHS England and NHS Improvement in response to the [LeDeR \(Learning Disability Mortality Review\) report](#).

This pilot programme is testing a hypothesis whether early interventions in the supported living sector can reduce mortality.

Why

The LeDeR report highlights the poor health outcomes experienced by people with learning disabilities, and the challenges they and their families and carers have in identifying signs of health deterioration early and preventing health problems.

The programme's ambition is to find new ways of working that could in future lead to fewer avoidable deaths of people with learning disabilities as an outcome of earlier interventions.

We want to work with people with learning disabilities, their families, and health and care staff to give them the confidence and skills to spot where things may be going wrong, and empower them to take action.

How

We are working with councils and health colleagues in the East and West Midlands, as well as people with learning disabilities and their families, to test and trial new tools, tech and processes.

People with a learning disability and their carers will, wherever possible, shape a way of working which they are happy to use.

At the end of the pilot, the aim is to recommend an existing, evidence-based product, methodology or tool that can be scaled up and rolled out nationally.

People with a learning disability and families/carers

This pilot is about how we can improve the ways we identify and respond to the declining health of a person with learning disabilities residing in a supported living environment.

We want to find out what you currently do if you or your family member with a learning disability starts to become unwell or poorly, and how you get help from others such as your GP, district nurse, or learning disability nurse.

By telling us about your experiences and ideas, the NHS and local authorities can improve the level of clinical care and support which is offered to people with learning disabilities.

Healthcare practitioners and supported living providers

This pilot is taking place across the West and East Midlands, to help anyone who lives or works with people with a learning disability to spot if they are becoming unwell, and know what to do to get the right medical help and support.

We want to identify clinician understanding and knowledge about the deterioration tools and checklists currently in use, capturing good practice and any areas for further enhancement.

Deterioration tools aim to reduce the chances of an adverse medical outcome by focusing on early recognition, timely and appropriate response, and clear communication through the right channels.

System/commissioning leads

The purpose of this pilot is to identify what deterioration tools and checklists are currently in use by organisations within our region, capturing good practice and any areas for further enhancement.

Deterioration can be defined as when a person moves from their normal clinical state to a worse clinical state.

This pilot is specifically looking at individuals with a learning disability residing in supported living environments, across the West and East Midlands.

At the end of the pilot, the aim is to recommend an existing, evidence-based product, methodology or tool that can be scaled up and rolled out nationally.

Audiences

Unless specified, these audiences are only being targeted in the pilot areas.

Priority audiences

- People with learning disabilities, families and carers involved in the pilot
- Supported living providers
- Primary care:
 - GP practices which work with the supported living providers in the pilot
 - Primary Care Networks
- Adult social care:
 - Learning disability teams across health and social care
 - Directors of adult social services in pilot areas
 - Local authority social care commissioners, contract managers, and quality assurance teams
- NHS:
 - Directors of nursing
 - CCG learning disability commissioners and learning disability health community teams
- Programme commissioners:
 - Regional commissioners of the LeDeR programme
 - National LeDeR team
 - National patient safety team

Other audiences

For awareness and public and patient involvement (PPI).

- Advocacy and patient groups:
 - Co-production groups
 - Advocacy groups and local care associations
 - Sub-regional Learning Disability and Autism Partnerships
 - Partnership Boards in the pilot areas
 - Individual advocates
 - HealthWatch
 - Public and Patient Involvement Groups
- Other interested stakeholders
 - Aligned research and academic stakeholders
 - Informatics and analytics teams from health and social care
 - Providers of digital technology
 - General public / media

Stakeholder analysis

Audience	Our ask/offer	Activity
People with learning disabilities, families and carers involved in the pilot	Explore opportunities to test tools through the pilot, with people with learning disabilities who require limited support, through to people with higher levels of need, who require far more support. Participate in the scoping survey.	Accessible Easy Read materials. Information for families to ensure they know about this work and can determine their role in co-producing solutions.
Supported living providers	How they can be involved and why they are so critical. How this programme is shifting perceptions and promoting safer care for people with a learning disability. Participate in the survey.	Briefing note introducing the programme and our approach. Team-specific materials material for training, information leaflets etc. Posters. Targeted webinars. Training sessions.
Primary care	Test the use of deterioration management tools of choice in the identified early adopter areas. Participate in the survey.	Briefing note introducing the programme and our approach. Team-specific materials material for training, information leaflets etc.

Adult social care	Work with key local teams, social workers, community nurses to ensure we garner their support by canvassing their views about the approach allowing the flexibility for them to shape it.	High-level briefing/presentation material introducing the programme and our approach. Engage with relevant councillors and committees, e.g. social care portfolio holders, Health and Wellbeing Boards, scrutiny committees, safeguarding adults boards.
NHS	Test the use of deterioration management tools of choice in the identified early adopter areas.	High-level briefing/presentation material introducing the programme and our approach.
Programme commissioners	Ensure aware and informed of progress.	Governance and performance updates. Support in the development of the final report and development of tools/toolkit.
Advocacy and patient groups	How this programme is shifting perceptions and promoting safer care for people with a learning disability. How they can be involved.	Web pages / content on partner websites. Case studies.
Other interested stakeholders	Updates on the programme, objectives and outcomes. Not immediately, but as the findings are shared, pre wider roll-out.	Web pages / content on partner websites. Case studies.

Channels

NHS England and NHS Improvement Midlands Region

Key channels available to the partners, relevant to this programme.

East Midlands AHSN

- Website - dedicated programme web page and news/event updates
- Patient Safety newsletter (quarterly)
- Corporate EMAHSN newsletter (bi-monthly)

West Midlands AHSN

TBA

East Midlands ADASS

TBA

West Midlands ADASS

TBA

Timeline

Date	Activity	Notes	Lead
Oct - Dec 2021	Identifying suitable test sites		
May 2022	Test bed work should be evidenced along with a report on the recommended approach to be adopted and in what circumstances. This will provide the required evidence base to inform a national managing deterioration strategy for people with a learning disability.		

Evaluation

How will we measure the effectiveness of our communications?

Document version control

Version	Date	Changes	Author
0.1	21/10/2021	Draft for comments.	BA
0.2		Updated draft.	

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