Living and Dying Well with Frailty Collaborative

Guidance document

August 2019

This document introduces the Living and Dying Well with Frailty Collaborative that focuses on improving identification and support for people living with frailty in the community so that they live and die well. The document outlines the content of the collaborative, the timescales and the requirements for joining.

This document is intended for anyone who works as part of a health and social care team who may be interested in joining the collaborative, such as a GP, community-based health or social care professionals, and for people who have a service planning role in an NHS board or Health and Social Care Partnership.

Contents

About the collaborative

Mission statement for collaborative

The purpose of the Living and Dying Well with Frailty Collaborative is for participating teams to improve how they identify and enable people aged 65 and over to live and die well with frailty in the community.

The collaborative focuses on people aged 65 and over as this is the target population for the Electronic Frailty Index (eFI). To be part of the collaborative, teams are required to use the eFI.

Benefits of collaborative

By joining the collaborative, Health and Social Care Partnerships (HSCP), GP practices and community teams will be supported to improve the effectiveness of local and strategic resources so that people receive the care they need at the right time. Participating teams will see the following benefits:

Clinical care benefits

- Support to use and interpret the eFI through the Scottish Primary Care Information Resource (SPIRE) so that teams can improve how they identify people living with frailty in their community who are likely to have increased levels of need and make greater use of unplanned services.
- Improve quality of life for people living with frailty by understanding which individuals within your population are experiencing a change in their level of frailty and could benefit from earlier intervention.
- Guidance on multi-disciplinary working to harness the potential of community support and assign the right roles to the right people.
- Guidance and materials to improve anticipatory care approaches that put the person with frailty at the centre of decision making and improve a person's experience if and when they encounter transitions of care.
- Guidance for adopting a realistic medicine approach to ensure appropriate care for a person with frailty.
- Improvement and analytical expertise to demonstrate the impact of your work through data and evaluation techniques.

Benefits for teams participating in collaborative

- Learn from clinical and topic experts relating to living and dying well with frailty.
- A platform to share your innovations and improvements with a national audience.
- Opportunities to meet and learn from peer teams throughout Scotland.

- A structure to learn about quality improvement and how to apply it in your work, including:
    - access to national data and measurement experts,
    - access to national quality improvement experts to test, implement and scale ways of working, and
    - information on links to professional development and quality improvement related financial incentives.

Aim

The collaborative aims to improve earlier identification, anticipatory care planning and shared decision-making, and support a multidisciplinary approach so that people living with frailty get the support they need, at the right time, at the right place.

The aim of the collaborative is to deliver three measures by November 2020:

Measure	Rationale
Reduce the rate of hospital bed days per 1,000 population for people aged 65 and over by 10%.	Measure will serve as a proxy for showing how people spend more time living in the community with fewer moments of crisis.
Reduce the rate of unscheduled GP home visits per 1,000 population for people aged 65 and over by 10%.	Measure will capture the change that occurs in the community as people experience fewer incidents of unplanned service use and GP practices reduce their unplanned workload.
Increase the percentage baseline of Key Information Summaries (KIS) for people living with frailty by 20%.	Measure will serve as a proxy to show how people living with frailty are involved in decisions about their care.

Measures

Teams will need to sign up to the three main measures of the collaborative so that the impact of the work can be recorded over time.

Teams will be supported to define additional outcome and process measures to reflect the local aim and interventions that are specific to their work. In addition to the local quality improvement and data analysis support, Healthcare Improvement Scotland's Improvement Hub (ihub) will advise on options for establishing local aims and measures specific to local interventions and provide templates to help design measurement plans.

Interventions

To deliver the aims of the collaborative, teams will focus on four drivers for change:

- Identify people aged 65 and over living with frailty in the community.
- Support people living with frailty to plan for their future care needs, and when appropriate, death.
- Support people living with frailty to access preventative support in the community.
- Develop effective multidisciplinary team working focused on person-centred, preventative care.

In order to identify the interventions to be used by teams, a review of evidence relating to community-based interventions was undertaken by Healthcare Improvement Scotland. The review looked at evidence for community-based interventions for people living with frailty, focusing on the prevention of harm or poor outcomes, and supported by relatively high-level evidence. The interventions are summarised in the driver diagram on page 6, the Living Well in Communities with Frailty - Evidence for What Works document is available on the ihub website.

Teams will decide the activities they wish to deliver that are linked to the four drivers for change, but will be asked to commit to at least the following elements of the change package:

- Use the Electronic Frailty Index (eFI) through SPIRE to identify people living with frailty aged 65 years and over.
- Engage in anticipatory care planning conversations with people living with frailty and record the information in the Key Information Summary (KIS).
- Work within a multidisciplinary team to consider the holistic needs of the person.*
- Use quality improvement methods to structure the work, including using data to learn how changes are being implemented and the impact they make.

*A multidisciplinary team refers to a group of professionals from various disciplines working together to deliver care and support that addresses a person's holistic needs.

The driver diagram on page 6 summarises the theory of change for the collaborative to deliver its aim of enabling people living with frailty to live and die well. Working from left to right, it outlines how the aim is delivered by focusing on four key areas of change (primary drivers). The activities related to each area of change are listed on the right of the diagram (secondary drivers).

For more information on driver diagrams please visit NHS Education for Scotland's website.

Outcome

Primary driver

Secondary drivers

Identify people aged 65 and over living with frailty in the community.

- 💡 Case find people at risk using the e Frailty Index
- Create diagnosis for frailty
- Multi-dimensional assessment
- Monitor change and deterioration over time

People 65 years and over with frailty, will experience a good life and death, including more time at home or in a homely setting.

- Reduce unplanned hospital bed days
- Reduce unscheduled GP home visits
- Increase use of anticipatory care planning and Key Information Summary

Support people living with frailty to plan for their future care needs, and when appropriate, death.

- 💡 Anticipatory care planning conversations, including recording information in the Key Information Summary
- Carer's assessment
- Informal/Adult carers support planning

Support people living with frailty to access preventative support in the community.

- Key worker
- Exercise interventions and physical activity
- Lifestyle and nutritional interventions
- Polypharmacy review
- Reablement
- Vaccinations
- Community-based geriatric services
- Palliative and end of life care

Develop effective multidisciplinary team working focused on person-centred, preventative care.

- 💡 Communication and collaboration within a multi-disciplinary team, including a multidisciplinary review
- Understand what support is available in communities and how to access support
- 💡 Use quality improvement methods, including data over time, to drive improvement

💡 Essential activity for all members of the collaborative

6

Links to national policy and programmes

The aims of the collaborative complement a number of national policies and programmes. Although not an exhaustive list, these include:

Scottish Government's 2020 vision, that everyone be able to live longer, healthier lives, at home or in a homely setting, and the **Health and Social Care Standards**: my support, my life:

1. I experience high quality care and support that is right for me
2. I am fully involved in all decisions about my care and support
3. I have confidence in the people who support and care for me
4. I have confidence in the organisation providing my care and support
5. I experience a high quality environment if the organisation provides the premises

National clinical strategy – focuses on prevention and maximising the effectiveness of community-based health and social care professionals by understanding the population's needs.

Strategic framework for action on Palliative and End of Life Care - emphasis on early identification and good co-ordination of care for anyone who would benefit from a palliative approach.

Palliative Care Directed Enhanced Service Scheme in Scotland - focuses on using tools such as eFI to identify people who would benefit from a palliative approach at an early stage, and encouraging person-centred assessments and Anticipatory Care Plans (ACP) which should be shared through the Key Information Summary (KIS).

Daffodil standards - a blend of quality statements, evidence-based tools, reflective learning exercises and quality improvement steps related to end of life care which are supported by Royal College of General Practitioners and Marie Curie.

A fairer Scotland for older people – a framework for action – promotes the value of multidisciplinary team-working and integrated community teams as a means to supporting people who are frail and/or with complex needs.

Frailty at the front door – a national collaborative, hosted by the ihub, which aims to improve identification of frailty, similar to the Living and Dying Well with Frailty collaborative, but is focused on acute care at the hospital front door.

LifeCurve – a model for understanding the order of functional decline that people with frailty experience.

Introduction to Frailty and the Electronic Frailty Index (eFI)

About frailty

Most definitions consider frailty a form of complexity, associated with developing multiple long-term conditions over time leading to low resilience to physical and emotional crisis and functional loss leading to gradual dependence on care. In many ways it is progressive like a long-term condition and tools such as the LifeCurve help to explain the decline associated with frailty.

In addition to health related problems, several social factors, such as social isolation and deprivation, can increase the likelihood of someone becoming frail. Although frailty is most commonly associated with older people, it is not defined by age; people living in areas of deprivation are more likely to become frail at a younger age compared to people living in less deprived areas.

The Dalhousie University clinical frailty scale explains the different stages of frailty that people experience.

Clinical Frailty Scale

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4 Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia
The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia,** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia,** they cannot do personal care without help.

Timely identification of frailty, and targeting individuals with evidence-based interventions, can reduce the complications of frailty and support the management of people's health[1]. Frailty is a progressive condition, which means it is important to provide people with information and support as early as possible, when the potential for improving health and

wellbeing is greatest. Identifying people at the different stages of frailty is crucial for ensuring that people are supported before crises occur or to slow progression of frailty.

To support teams and organisations in Scotland to identify their frail population, a version of the eFI is available through SPIRE. Using the eFI through SPIRE enables teams and organisations to undertake a population level assessment and focus preventative support on those people who are likely to benefit the most.

The eFI

The eFI is a clinically validated tool that uses existing electronic health record data to detect and assess the severity of frailty. It uses a cumulative deficit model of frailty, in which frailty is defined through the accumulation of deficits, which can be clinical signs, symptoms, diseases and disability.

It comprises 36 deficits, which have been developed using GP read codes. A person's frailty score is calculated by dividing the total number of deficits that they have by the total number of possible deficits. The score is a reliable predictor of those who are at risk of adverse outcomes, such as care home admission, hospitalisation and mortality.

The Scottish version of the eFI has been developed to identify not only the total number of people who are mild, moderate and severely frail, but also generates a list of high priority people based on the change they have experienced during a six month period.

The eFI enables teams to target people based on their condition and level of need as opposed to a service perspective of risk. Combined with preventative interventions the tool has the potential to transform care for older people living in the community.

Access to the eFI

Using the eFI to identify people living with frailty is one of the compulsory elements of the collaborative. The eFI is accessed through the Scottish Primary Care Information Resource (SPIRE). Teams that are interested in applying for the collaborative should check that they have access to SPIRE and can use the eFI report.

Further information about eFI can be found on the ihub website. Screenshots of the report are available on page 7 onwards in the Frailty and Electronic Frailty Index document.

If you do not have SPIRE or have any questions relating to SPIRE, please contact your local eHealth Facilitator.

Participating in the collaborative

Collaborative timescales

The key dates listed below are essential to the collaborative. The Away Team must attend all sessions.

The Away Team and Home Team are defined as follows:

- **Away Team –** The Away Team represents and provides leadership to the Home Team throughout the collaborative. They attend all learning sessions and work with the home team to implement the change ideas. The Away Team receives improvement and clinical expertise from the ihub.
- **Home Team –** The Home Team refers to the health and social care professionals who are involved in implementing the change ideas. This includes the health and social care teams delivering care and support to people with frailty. The Away Team works with this team throughout the collaborative.

During the collaborative there are national learning sessions that bring together the Away Teams to learn and share. Between the learning sessions there are action periods where teams will share the learning with their Home Team and progress their improvement work. During the action periods, there is a requirement to submit progress reports which includes local data. There may also be local or regional meetings or events.

Key dates:

Session	Date
Introductory WebEx	27 August AM or 28 August PM
Learning Session 1	19 September 2019
Learning Session 2	27 February 2020
Learning Session 3	June 2020
Learning Session 4	October 2020

The WebEx is an online meeting. The learning sessions are events that must be attended in person, as remote dial in will not be possible.

Action periods and learning sessions

Away Teams that join the collaborative will develop a plan to test their idea. A project charter helps teams to structure their plan and record the following information:

- collection of baseline data for the three overarching measures
- description of local aim
- confirmation of target population and intervention(s)

- description of initial activity, and
- confirmation of how the work fits Equality Impact Assessment (EQIA) guidelines.

The National team and local quality improvement lead would support the team to structure their work using an improvement approach.

Description of action periods and learning sessions:

Collaborative phase	Description
Initiation phase Initial testing	Complete project charter and capture baseline data.
Learning session 1 19 September 2019	Training on quality improvement methods, including using data to understand how your interventions are being implemented and the difference they make.
Action period 1 Refine and implement	Implement first test idea with starting GP practices. Study learning from initial test and reflect on success and challenges of change ideas.
Learning session 2 February 2020	Teams present their progress and share experience of testing their change idea. Training on how to increase the size of improvement work so that it impacts on a larger population.
Action period 2 Begin involving more GP Clusters and community team from your Health and Social Care Partnership	Refine ideas and test again before implementing way of working with starting population. Prepare conditions for increasing number of teams included.
Learning session 3 June 2020	Teams present their progress of implementing the new way of working and their plans for increasing the size of their work. Training on how to document and articulate your improvement work using evaluation methodology.
Action period 3 Adopt way of working across Health and Social Care Partnership	Increase number of teams included in activities so that improvements reach a larger population (scale). This could involve including additional GP Clusters and community teams in the change ideas.
Learning session 4 October 2020	Teams share experience of increasing the scale of their activities. Celebration and close of national collaborative.

Who is involved in the collaborative

Sponsor roles

The multidisciplinary nature of the collaborative means that sponsorship is needed for the diverse range of professionals involved. A clinical and Health and Social Care Partnership sponsor will therefore be asked to:

- represent and provide strategic direction to the GPs who are involved in the collaborative (clinical sponsor)
- represent the Health and Social Care Partnership for which the test team is located (Health and Social Care Partnership sponsor)
- be ultimately responsible for progress of test team, and
- resolve risks or issues that prevent the test team from progressing.

Away Team

The Away Team should be made up of a maximum of 6 people and should attend all collaborative key dates listed in the collaborative timescales section of this document. This team is expected to support the health and social care professionals implementing activities in the community to plan, test, learn from, and implement their change ideas. The Away Team represents the Home Team at learning sessions and ensures that information is shared throughout the collaborative. At the relevant point in the collaborative this team will also be responsible for increasing the size of the improvement activities by involving additional GP practices and community teams. As a minimum the Away Team should include:

- **Health and Social Care Partnership Lead**
  A person from the Health and Social Care Partnership who has the authority to decide how relevant community resources are used. This could be someone who is a Locality Manager, Older People Service Manager or similar role in your partnership.
- **GP Representative**
  A GP from one of the GP practices participating in the collaborative from the beginning. There is funding available for one GP from each Away Team to attend the learning sessions as detailed in the funding section of this document. This person will represent the work at learning sessions and be able to make decisions about the activities taking place in their area.
- **Quality Improvement Lead Role**
  As a minimum they should understand the Model for Improvement Framework and/or have experience of supporting teams to change ways of working. This person will help the team to plan, test, learn from, and implement their activities using a structured approach. The person will provide day to day support to the team of health and social care professionals and will be supported by the ihub improvement staff who will be available to advise on the structure of the improvement activities. This does not need

to be someone with improvement in their job title, but may be someone who has completed quality improvement training such as, but not limited to, Scottish Improvement Leaders Programme (ScIL).

- **Data Lead Role**
  A person who can support the team to collect, analyse and report local data so that they can understand how their activities are being implemented and the difference they make. This is crucial for enabling teams to make informed decisions about their change ideas.

The remaining two team members should include people from the GP practices and community teams who will be able to share insights into the activities being implemented.

Coordinator Role

For the duration of the collaborative the coordinator is the first point of contact for the Away Team and national team. This role includes liaising between the teams, setting up meetings and calls, and coordinating and submitting reports to meet deadlines. This person should have access to, or be able to coordinate diaries for all members of the Away Team. This person does not need to be a member of the Away Team and does not need to attend the learning sessions.

Funding

The collaborative will be free to access for successful teams. The ihub provides improvement and national clinical staff time to support teams throughout the duration of the collaborative.

In addition, each participating team is entitled to receive up to £1,296 for the financial year ending March 2020. This funding is a contribution towards protected time for the named GP representative to attend the first two learning sessions and regional meetings. The Healthcare Improvement Scotland rate is currently £216 per session (half day), this funding will provide locum cover for three full days of GP backfill. The funding will be allocated in line with Healthcare Improvement Scotland's processes.

Funding after April 2020 will be confirmed at a later date.

For more information about the collaborative, get in touch by emailing hcis.livingwell@nhs.net.

References

1. Beswick, A.D. et al. Complex interventions to improve physical function and maintain independent living in elderly people: a systematic review and meta-analysis. *Lancet*. 2008;371:9614 725–735

Improvement Hub
Healthcare Improvement Scotland