

Improving palliative care for people with learning disabilities in Scotland policy and practice



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Policy Drivers

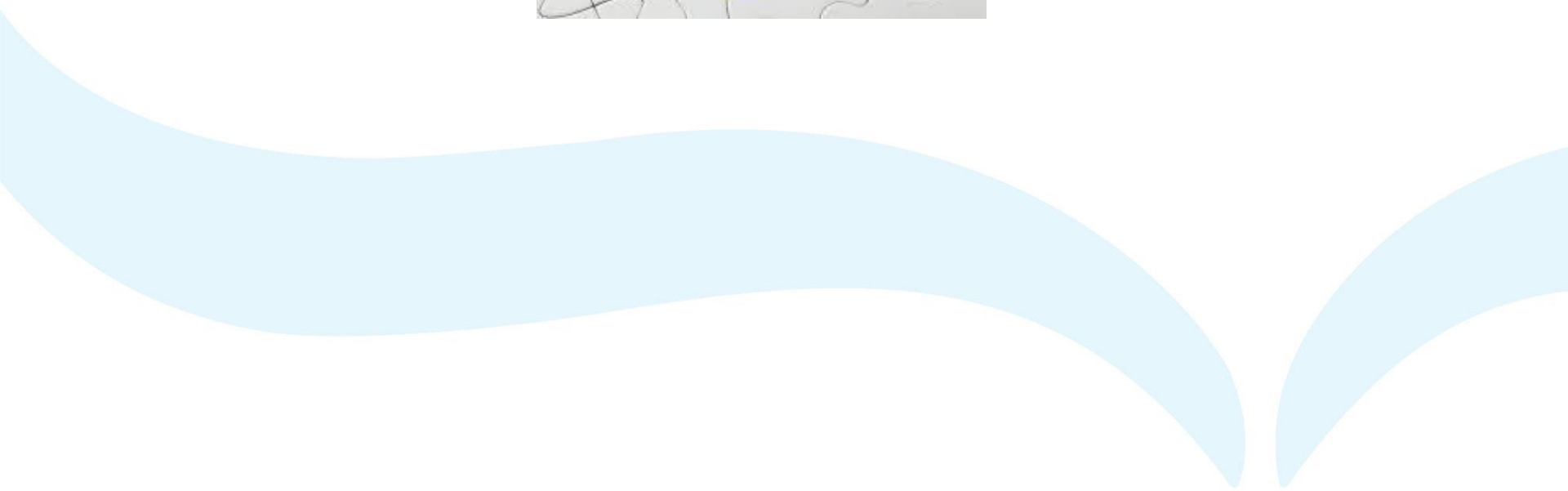


- Living and Dying Well 2008
- 2020 Vision for Health and Social Care (2011)
- Keys To Life (2013) Recommendation 26
- The Social Care self directed support (Scotland) Act 2013
- The Public bodies (Joint working) (Scotland) Act 2014
- Grasping the Nettle- Scottish Partnership for Palliative Care (2015)
- Strategic Framework for Action on Palliative and End of Life Care (2015)
- Health and social care Delivery Plan(2016)
- Palliative and End of Life care :enriching and improving experience (2107)



Learning Disability and Palliative Care

- Increasing population
- Poorer health and more complex health issues. Life limiting illness more prevalent
- Multiple Co morbidities
- High incidence of premature deaths in LD population
- Health Inequalities and Discrimination
- Different disease profiles
- Diagnosis difficult



LIVING AND DYING WELL

A national action plan for palliative and end of life care in Scotland 2008.

“To ensure that all health and social care professionals are equipped with the knowledge, skills, competence and confidence to care for the diversity of patients and families living and dying from advanced, progressive or incurable conditions.”

“The sharing of skills and expertise and the opportunity for dialogue and the sharing of educational opportunities between healthcare teams can greatly enhance competence and confidence.”



2020 Vision for Health and Social Care



The Scottish Government's 2020 Vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting and, that we will have a healthcare system where:

- We have integrated health and social care
- There is a focus on prevention, anticipation and supported self-management
- Hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm
- Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions
- There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate, with minimal risk of re-admission

Keys To Life (2013)

The Keys to life is
Scotland's Learning
Disability Strategy



The keys to life

Grasping the Nettle

Our vision is that Scotland will be a place where:

- people's wellbeing is supported even as their health declines;
- people die well;
- people are supported throughout bereavement.



The Strategic Framework for Action



The Strategic Framework for Action outlines the key actions to be taken that will allow everyone in Scotland to receive services that respond to their individual palliative and end of life care needs. It is supported by £3.5 million funding over four years which will be used to drive improvement across the sector and support targeted action on training and education. The Framework will also work to drive a new culture of openness about death, dying and improvement.

Health and Social Care Integration



“We want to ensure that adult health and social care services are firmly integrated around the needs of individuals, their carers and other family members; that the providers of those services are held to account jointly and effectively for improved delivery; that services are underpinned by flexible, sustainable financial mechanisms that give priority to the needs of the people they serve rather than the needs of the organisations through which they are delivered; and that those arrangements are characterised by strong and consistent clinical and professional leadership.”

Palliative and End of Life care: enriching and improving experience

- Identify the knowledge and skills required by health and social care staff.
- Education including mandatory CPD
- Partnership and Collaborative Working





- Access to all-challenging inequality
- Identifying those in need
- Collaborative working
- Prevention. Anticipation.
- High quality person centred care irrespective of setting
- A range of experts-Staff from health, social care and third sector providing care
- Support of communities , families and carers alongside formal services
- Cultural changes-Openness about death and dying
- Education. Training. Development of staff
- Care provided in communities
- Flexible, sustainable finance
- Join up services
- Individual control - Supported self management
- Strategic plans, research , resources

Palliative Care



An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

**World Health Organisation
2010**

End of Life Care

People who are approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent(expected within hours or days) and those with:

- Advanced progressive incurable conditions
- Generally frail and co existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life threatening acute conditions caused by sudden catastrophic events”

National Council for palliative care

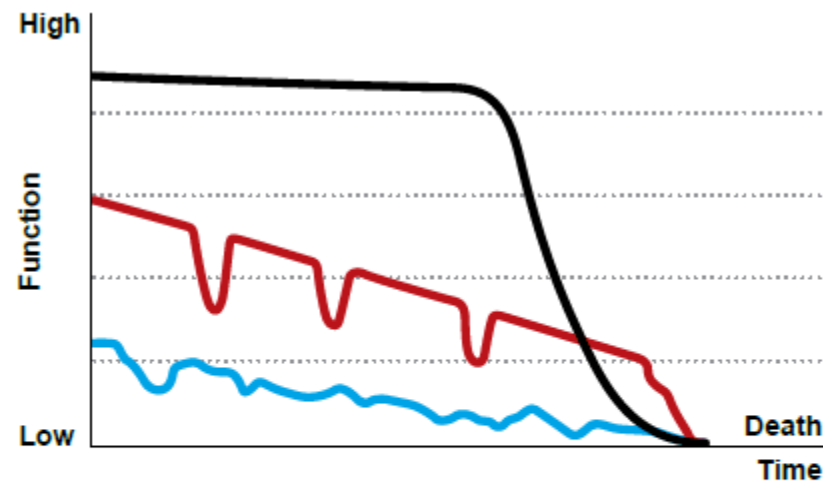
The palliative care framework



The palliative care framework supports people irrespective of stage of disease or condition :

- early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy,
- living with complex health needs and co morbid conditions
- living with chronic disease
- approaching end of life care and
- support for those who grieve

Trajectory in palliative care



Source: Murray, S.A. et al'

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

Health Needs Assessment for palliative and end of life care in NHS Greater Glasgow and Clyde (NHS GGC)

Dr. Beatrix v. Wissmann, Public Health Registrar, NHS GGC .Dr. Emilia Crighton, Consultant in Public Health Medicine, Deputy Director of Public Health NHS GGC

- Conservative estimate that 76% deaths were due to underlying causes which are likely to benefit from some degree of palliative and end of life care
- A substantial shift in place of death from hospital to communities
- Prognostic Indicators
- Lives lived in communities

Palliative Care – Everybody's Business

- Anticipatory care planning
- Difficult conversations
- Health advocacy
- Support the individual to gain an understanding of condition and prognosis
- Decision making and Choice
- Dignity and Value
- Joint Assessment -Person centred, holistic assessment of physical, social, emotional and spiritual aspects of care
- Coordination of care and health advocacy
- Partnership and collaborative working to improve patients outcomes
- Better outcomes for the individual and those who care for them

Linda McEnhill Winners 2013

**Learning Disabilities and Palliative Care- Building
Bridges: Supporting Care**



Greater Glasgow and Clyde
and The Prince and Princess
of Wales Hospice Glasgow

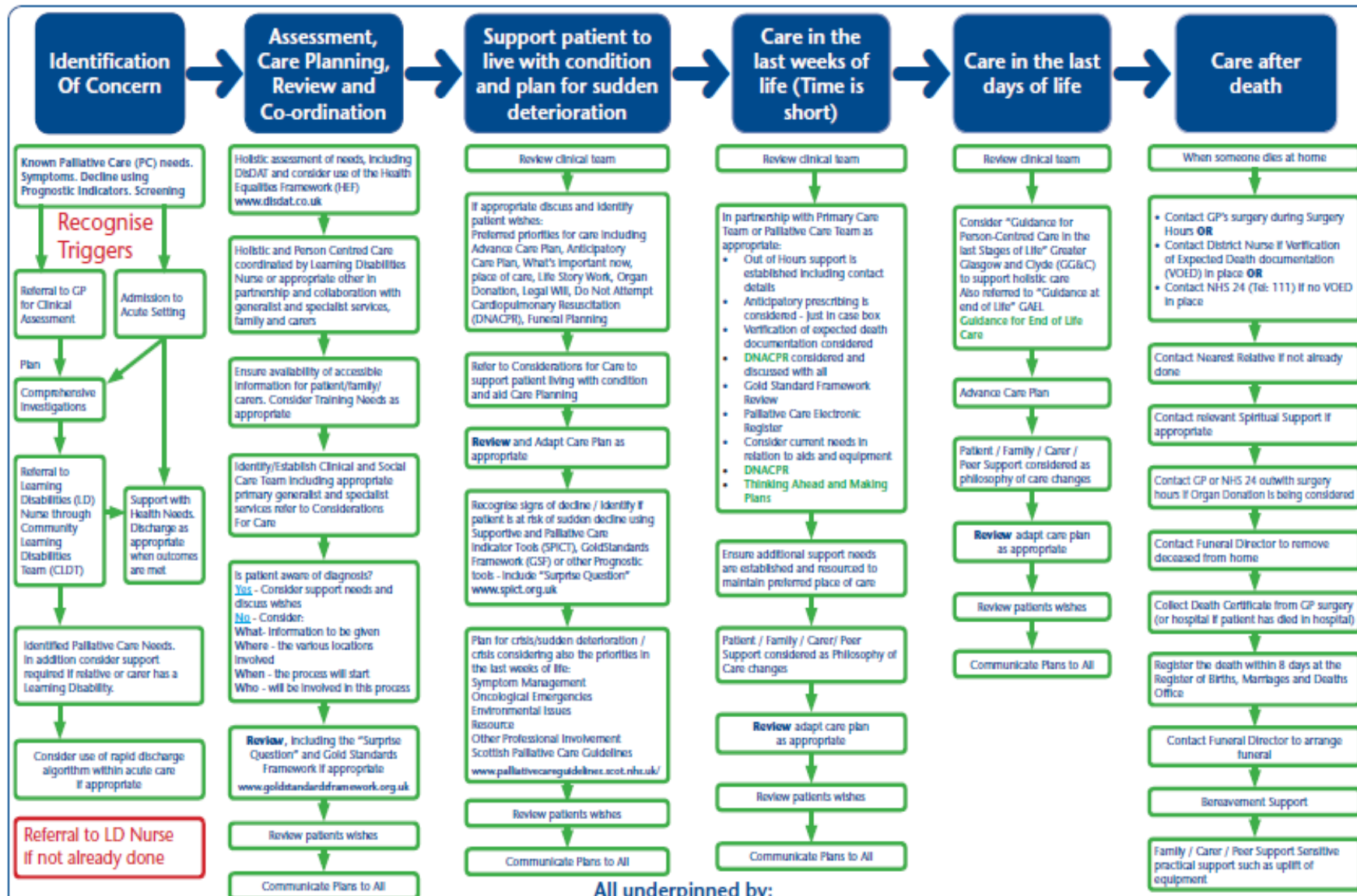
Linda McEnhill Winners 2013 Doris's Story

Key Community Supports
West Dunbartonshire



Supporting people with learning disabilities through the palliative care journey

NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway



All underpinned by:

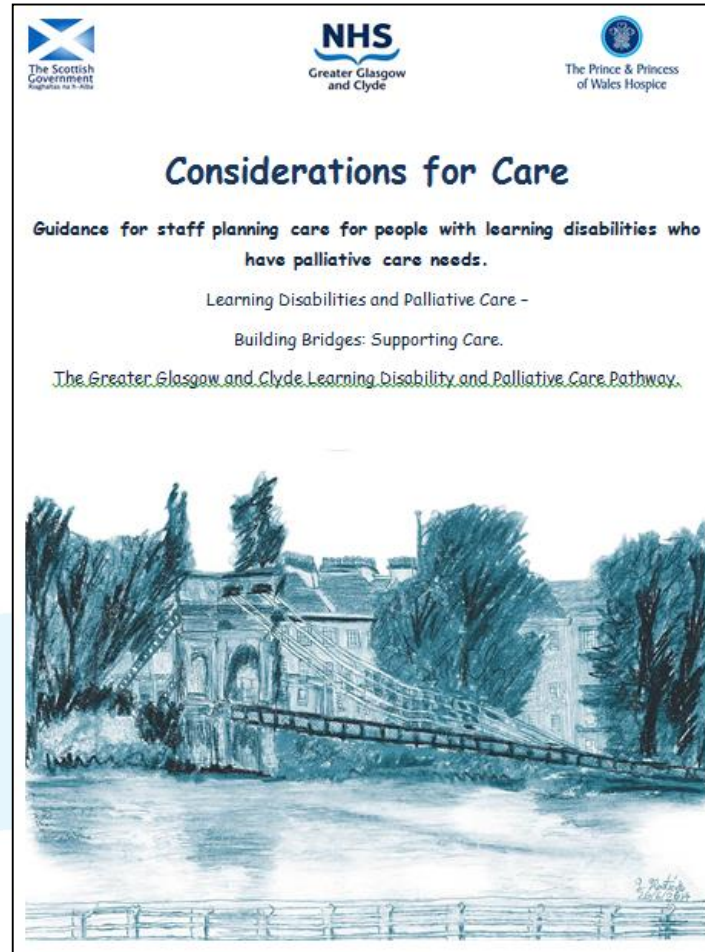
Legal framework

Communication

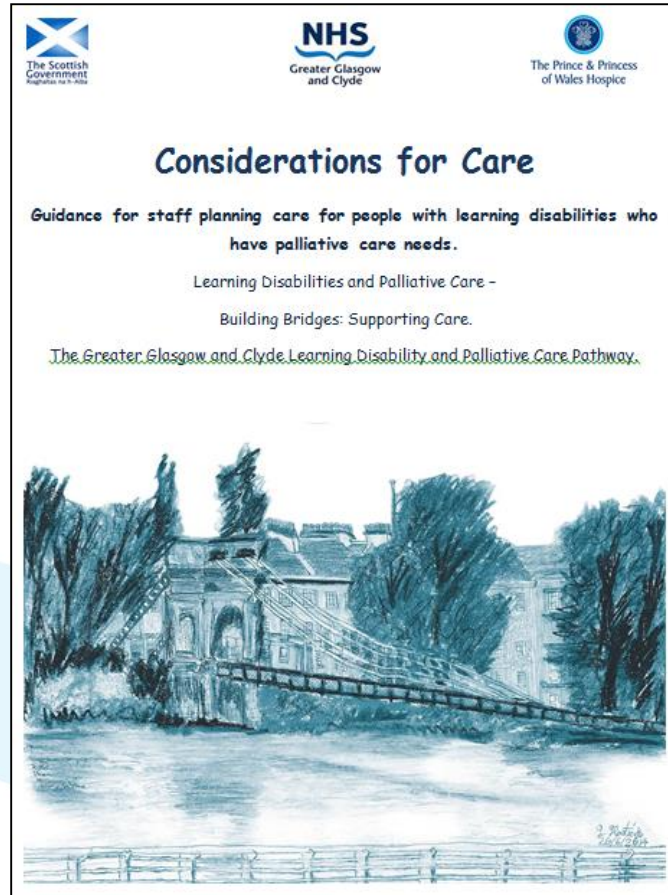
Collaboration

Co-ordination

A skilled, knowledgeable and confident workforce :



Mapping Educational Needs



Anticipatory Care Planning



**Robust Regular
Review**



Key Practitioners

Lay the foundations for partnership working between Learning Disability and Palliative Care Services to enhance the patient's experience

- **Link** to Specialist Team.
- Implementing evidence based practice.
- Bridge the gap between theory and practice.
- To improve quality of care.
- Improve communication.
- Sharing knowledge and expertise



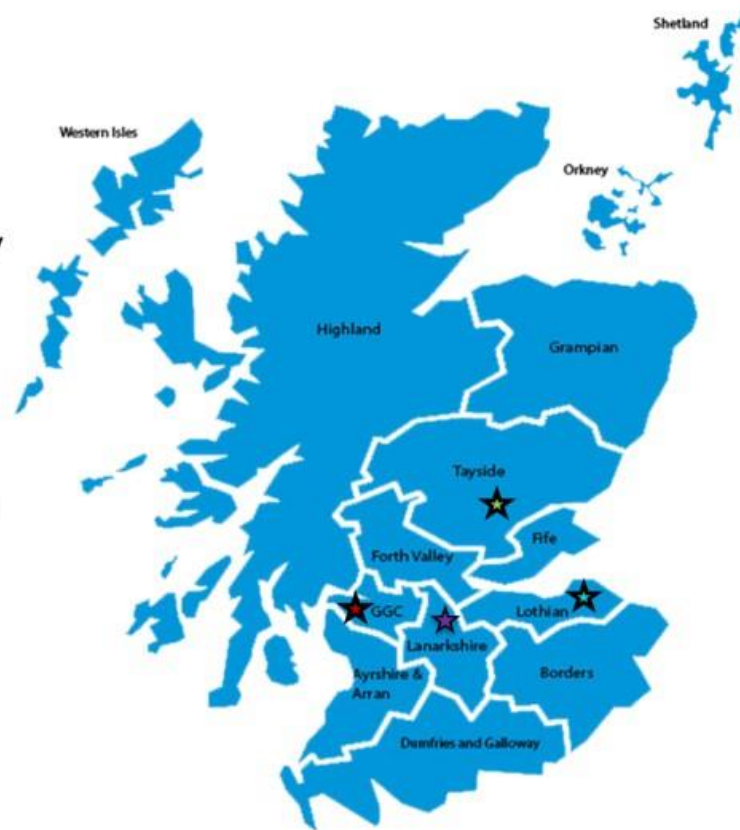
Learning Disability Managed Clinical Networks (South East of Scotland)

West Region:

Ayrshire & Arran
Dumfries & Galloway
Greater Glasgow &
Clyde
Lanarkshire

South & East Region:

Borders
Fife
Forth Valley
Lothian



North Region:

Grampian
Highlands & Islands
Tayside

High:

★ The State Hospital (TSH)

Medium:

★ Orchard Clinic (Lothian)
★ Rohallion (Tayside)
★ Rowanbank (GG&C) &
National ID

Low:

Most Health Boards

Glasgow and Clyde Palliative Care Network Group

- 6 Adult Hospices
- Acute care
- Primary care
- Care homes /
nursing homes
- Specialist services
Learning Disability /
Mental Health



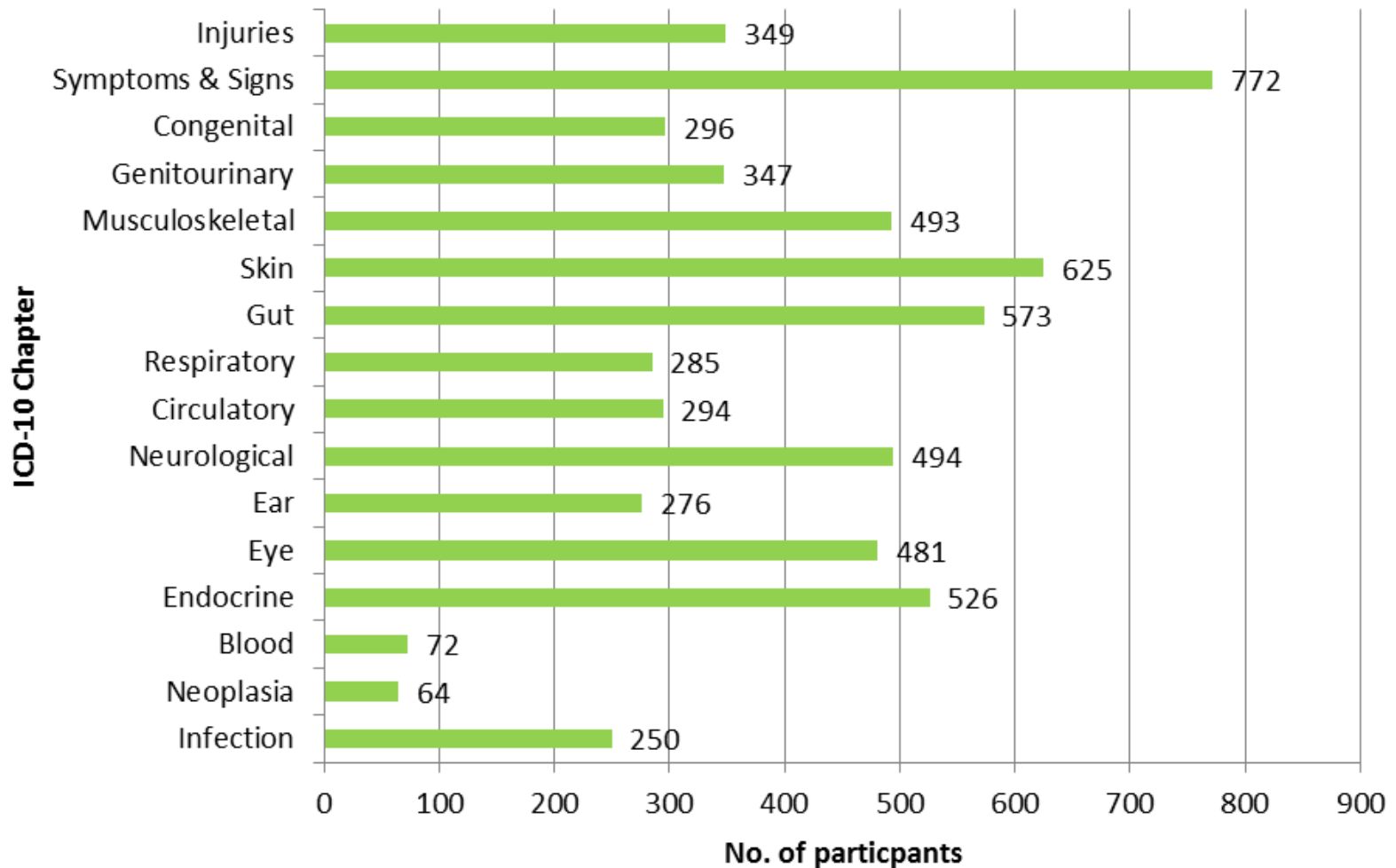


Scottish
Learning Disabilities
Observatory

The most prevalent physical health conditions

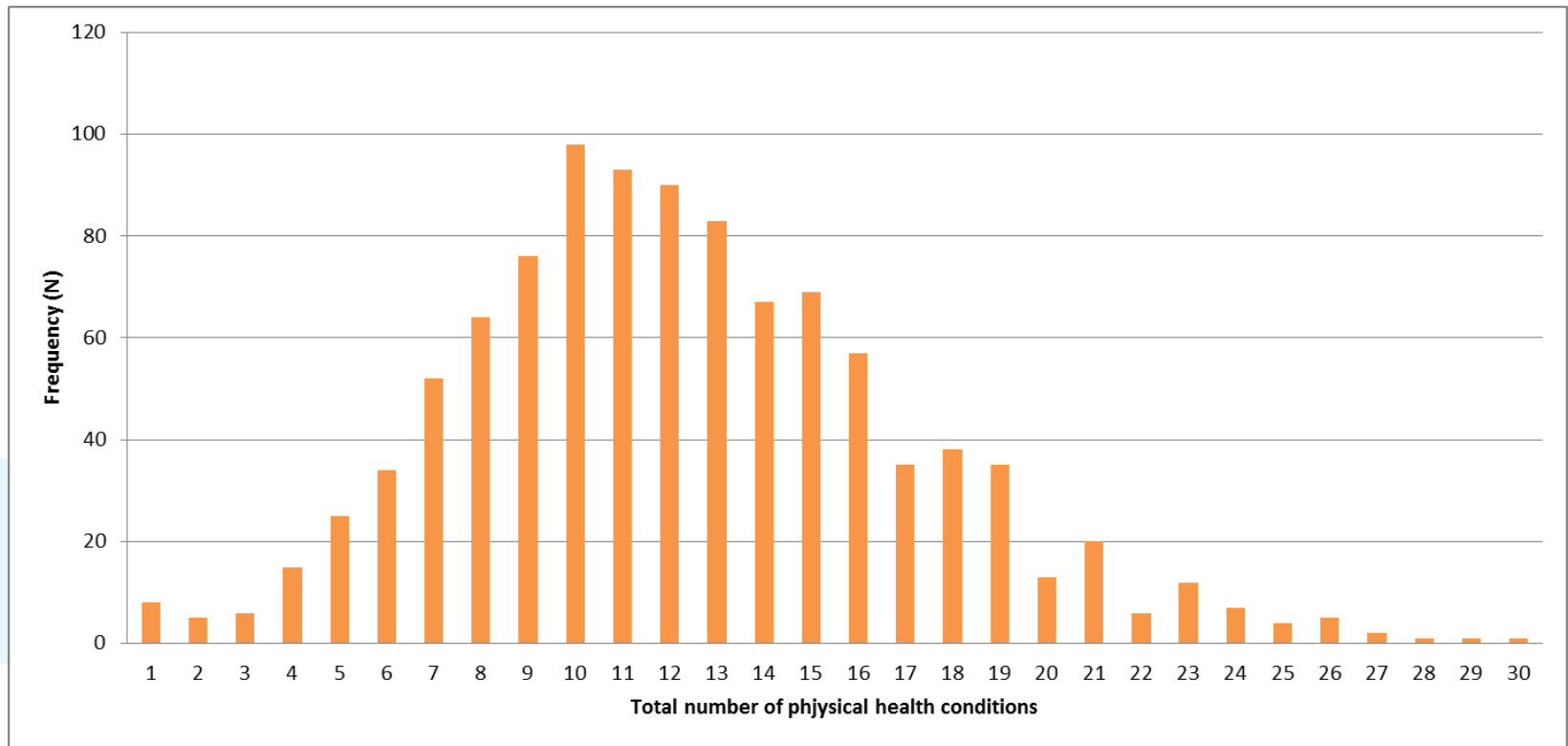
Learning Disability Observatory Glasgow

Physical health conditions by ICD-10 Chapter



The extent of multi-morbidity

Learning Disability Observatory Glasgow



Linda McEnhill Winners 2014

pamis
promoting a more inclusive society



Peaceful pain free and dignified



Authors, Jill Ferguson and Val Laurie, work for Scottish Autism and have written this inspiring book to share their learning so that other teams can deliver peaceful, pain free and dignified end of life care to individuals with autism.



RESPONSIBILITY
starts with **ME**



Thank you
and
Lang may
yer lum
reek

Allison

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**ALLISON O'DONNELL PRACTICE DEVELOPMENT NURSE
SPECIALIST LEARNING DISABILITY SERVICES
GREATER GLASGOW AND CLYDE**