An Roinn Sláinte
Department of Health

The testing and results of an integrated nurse-led community virtual ward proof-of-concept.

Chief Nursing Officer's Office, Department of Health & Office of the Nursing and Midwifery Directorate, Health Service Executive

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Foreword from the Chief Nursing Officer

I am delighted to present this report on the testing of a proof of concept (POC) of an integrated nurse-led community virtual ward (CVW). This innovative approach to care provides greater access and choice to support people to self-manage and live independently and facilitates integration of services at greater value for money. Testing a proof of concept CVW determined the design and functionality of the model of care and examined how we can maximise on the nursing response to Sláintecare, including the role of the Enhanced Nurse (EN). The POC CVW has assisted in setting out the direction for policy in delivering acute care in the community. In delivering acute care in the community, a CVW must meet the needs of the population and support patients at home. As such, the model has been developed with the direct engagement of patients, including their experiences following admission to the CVW, to facilitate a co-design approach to the model. This is in addition to clinician feedback to ensure the model is sustainable and scalable. The report outlines the key pillars required to deliver a CVW in the community, including governance and integration that is enabled by technology. The testing of this POC would not have been possible without the dedication and input of service leads and frontline staff whose care, compassion and commitment drove this innovation from idea to implementation and evaluation. I would like to thank Dr Clare Lewis & Ms Karolina Farrell (Chief Nursing Officer's Office) and Ms Margaret Casey (ONMSD) as well as Royal College of Surgeons Hospital Group (Beaumont Hospital), Community Healthcare Organisation (Area 9 Dublin North Central and County), The Avenue Family Practice, Beaumont Park Clinic, The Edenpark Surgery and Coolock Family Practice. I would also like to thank the Clinical Governance Group, Mr Des O'Flynn, Ms Michelle Forde, Dr Maitiu Ó Faoláin (GP), Dr Breda Cushen, Professor Richard Costello, Dr Emmett O'Brien, Ms Karen Greene, Ms Melanie McDonnell, Ms Meabh Smith, Mr Eamonn Costello, Ms Rebecca Borton, Ms Deirdre Carroll, Ms Berneen Laycock, Ms Aisling Madden, Ms Deirdre Long, Ms Yvonne Whelan, Ms Yvonne Ryan, Ms Loreto Grogan and Ms Virginia Pye, whose expertise and input was essential to the development and testing. Finally, I look forward to further engagement with all our partners and stakeholders.

Ms Rachel Kenna

Foreword from the Director of the Office of the Nursing and Midwifery Services

In response to the HSE's Implementation Plan for the LCR Nursing Agreement, I am pleased to present this report on the pilot testing of "An Integrated Nurse Led Community Virtual Ward" proof of concept (POC).

The Community Virtual Ward (CVW) is a relatively new initiative in Ireland that delivers a nurse-led approach to care and places the patient at the centre. It supports integration of care facilitating a seamless transition across acute and community enabled by a clear governance structure to ensure patient safety is central to model delivery. The CVW model will assist in the delivery of the objectives of Sláintecare to provide care closer to home and support patients to stay well in their own home for as long as possible. This approach to care provides an environment to ensure healthcare professionals are working collaboratively to provide the right skills, in the right place at the right time by engaging communities and Services to continue to face the challenges of ensuring timely patient discharge and managing the 'flow' of patients through their organisations while striving to achieve value for money. Innovations such as the CVW can create solutions and by working together acute and community services can learn from each other and work more efficiently and effectively in an integrated way.

Throughout this proof of concept, staff embraced new ways of working and any previous existing boundaries were dissolved to enable care to be delivered across acute and community services. The use of remote monitoring allowed clinical staff to review and update care plans for patients, regardless of which organisation the healthcare professional was located. With the support of Advanced Nurse Practitioners (ANP's), Community Intervention Teams (CITs), nursing and medical, CIT staff upskilled themselves to provide care in this new way of working. Support structures across the organisations were enhanced. This proof of concept test has provided the direction to embed the use of technology to assist and improve the patients' journey through the healthcare system.

This collaborative approach between the HSE's Oversight Group for the implementation of the LCR actions, ONMSD, CNO DOH and Services has been a key enabler in bringing this pilot initiative to fruition. The next step is to consider further testing of this way of working by extending the Community Virtual Ward to other sites as appropriate.

Finally, I would like to thank everyone who has contributed their time and expertise to work on this proof of concept test to explore how a Community Virtual Ward could work.

Dr Geraldine Shaw

Contents

Glossary of Terms

ANP	Advanced Nurse Practitioner
cANP	Candidate Advanced Nurse Practitioner
CIT	Community Intervention Team
COPD	Chronic Obstructive Pulmonary Disease
CVW	Community Virtual Ward
DECT	Digital Enhanced Cordless Telecommunications
ED	Emergency Department
EN	Enhanced Nurse
ENT	Ear Nose and Throat
GLAD	Geriatrician Led Assisted Discharge
GP	General Practitioner
HCP	Health Care Professional
HSE	Health Service Executive
ICU	Intensive Care Unit
IHI	Individual Health Identifier
LCR	Labour Court Recommendations
MDM	Multidisciplinary Management
NMPDU	Nursing and Midwifery Planning & Development Unit
POC	Proof of Concept
QRSM	Quality Related Safety Measures
RGN	Registered General Nurse

Executive Summary

This report presents a model that will support the Enhanced Nurse (EN) role to practice to the top of their licence and deliver care that addresses the emerging needs of the population. This includes greater complexity of care needs and an increase in the quantum of services delivered across hospital and community settings. The fundamental objective of this report is to develop a nursing model which will assist with healthcare reform and support a shift in care to the community. This will align with policy and strategy such as Community Re-design and the Enhanced Community Care model as part of the Health Service Executive (HSE) National Service Plan (2021) and Sláintecare reform programme.

Why we need the Report

This report provides the basis to test policy in the context of a Community Virtual Ward (CVW). This includes the evidence presented in the literature and the infrastructure and resources required to deliver high quality and safe care to patients in their own homes. A key enabler to this is technology. It is important that we leverage technology to meet the needs of populations and avoid digital alienation. To reduce digital alienation, the report outlines a high technology and low technology approach to care delivered in the CVW. This is based on patients' experiences of using technology and remote monitoring devices, with attention on how it assisted them to understand and manage their condition. This also includes feedback from nurses' experiences of using the technology and sharing information across the hospital and community is presented. This is in addition to feedback from Consultants and General Practitioners and their experiences of the model of care. This is essential to inform how we; i) provide digitally enabled care to support patients, ii) support nurses and midwives to deliver safe, effective, and efficient care, and iii) provide a clinical governance model to move acute care into the community.

As the role of the EN develops and evolves, it is important to capture the essence and capability of the role and what can be achieved by a nursing workforce operating at this level. Therefore, the report outlines the nursing care that was delivered in the CVW by ENs. This includes the acuity and dependency level of patients, the assessment process and care bundles delivered in the context of chronic disease management.

1.0 | Introduction

There is increasing evidence that delivering care in a CVW benefits patients in areas such as chronic disease management and older persons care and supports a shift in care from the acute hospital to the community. The nursing workforce in Ireland is innovative, creative and highly skilled. As the EN role advances, the CVW has the potential to provide the necessary framework to support ENs to deliver structured care in the community during periods of illness and/or functional decline.

A patient centred focus is essential to the model in providing access and choice. This has never been more relevant than with the onset of COVID-19 and the need to deliver care differently, reducing face-face direct contact whilst continuing to provide care and keep people well and safe at home. As such, technology enabled care has flourished, providing remote monitoring technologies and video consultations. These new ways of working are inherent to address the challenges in the health and social care systems and have been delivered in CVW models internationally with positive outcomes. This includes reduction in unplanned hospital admissions and emergency department presentations and increased self-efficacy in chronic disease management (Lewis et al., 2013, Leung et al., 2015, Lewis et al., 2020a, Lewis et al., 2020b).

In addition to remote technologies, integration of care has been instrumental to the mobilisation of services in response to COVID-19. This has enabled an effective response to support residential care, testing centres and community assessment hubs. Therefore, the concept of integration of care was central to the POC CVW, with acute nursing services integrating with community nursing within the Community Intervention Team (CIT)[1]. The main objective of integrated care is to achieve better co-ordination of services by bringing together key aspects in the design and delivery of care systems that are patient centred. The integrated care model underpinning the CVW examined the design and delivery informed by the processes of care and outcomes of care. This was in addition to identifying the governance structure required and how shared care can be delivered across service boundaries.

What is a Community Virtual Ward

The CVW is a flexible and integrated model working across community and hospital settings, receiving admissions from both areas (Lewis et al., 2017). It is termed a CVW as the care is delivered in the community in the person's home and beds are not physical beds but virtual beds. The CVW operates similarly to a ward in that a team of nurses provide care for the duration of the admission. They measure haemodynamic status[2] and there is a higher level of monitoring and interventions than in usual care (considered as routine care received by patients for prevention or treatment of diseases, normally delivered by primary care with GP as clinical lead) that reflect the patient's care needs and

[1] A Community Intervention Team (CIT) is a nurse-led service that provides a rapid and integrated response to a patient with an acute episode of illness who require enhanced services/acute intervention for a defined short period of time.
[2] Hemodynamic status is the measurement of blood flow and can be assessed non-invasively with blood pressure measurement, assessment of heart rate, quality of the pulse rate, pallor and capillary refill (pressure applied to the skin measuring the time it takes to regain colour).

response. There is an escalation pathway to the acute hospital within the CVW that is activated by healthcare staff based on criteria including objective data and symptoms (Appendix 1 and 2). This is to ensure patient safety is maintained and that evidence of deterioration is acted upon by providing timely access to acute hospital care.

The care delivered in the CVW POC is a blend of specialist care prescribed by Advanced Nurse Practitioners (ANPs) and specialist generalist care prescribed and delivered by Registered General Nurses (RGN) and ENs working within the CIT service. This is a shared care approach, and the patient is central to the decision-making process. This provides a partnership approach to care and capitalises on the expertise of a nursing workforce operating across both areas. Delivering this approach to care means that the patient has access to a hybrid model. The hybrid model ensures the patient receives the best approach to care, synthesizing the expertise and knowledge across services to provide evidence-based care. This is coupled with the ability to navigate services and reduce duplication in relation to diagnostics and on-ward referral in the community. This is essential in terms of disease modification (treatments and interventions to reverse or affect the progression of underlying disease) and to reduce the requirement for unscheduled and scheduled care and waiting lists for services.

The purpose of testing a proof of concept Community Virtual Ward

The CVW was tested as part of the Implementation Plan for the EN role to facilitate a shift in practice to the community and support ENs to work at the top of their licence[3]. The CVW was tested as a proof of concept to examine design and functionality of the model before entering any larger-scale pilot testing. As part of the implementation plan for the Labour Court Recommendations (LCR21900) and testing the CVW, there were **two deliverables;**

i) To identify one pilot site (acute hospital and community) to test a Community Virtual Ward.
ii) To assess results of pilot and develop rollout plan to extend community virtual ward to other sites as appropriate.

The objectives were;

i) To test the delivery of acute hospital nursing services directly in the community working with a nurse-led community intervention team.
ii) To test the CVW model to include a combination of remote monitoring and direct face-to-face care in the community to support patients at home.

The method of testing a proof of concept was to evaluate a new approach to healthcare inclusive of technologies and establish the clinical feasibility. This method of testing has demonstrated what has worked well and lessons learned, using objective data and patient and clinician experience. It also assisted in evaluating potential costs inclusive of resources and cost efficiencies when compared to acute hospital care.

To determine governance (accountability and responsibility for patients admitted to the CVW) of the model as part of the test, a clinical governance group was established. The clinical governance group reviewed the aims and objectives of the CVW, target populations, types of interventions and level of access that would be required. This also included the level of integration required to deliver on the model from a community perspective, and how technology would be

[3] Practicing to the top of their licence means that activities should utilize the full extent of their education, training, and experience.

leveraged to support patients at home.
The CVW will offer two pathways of care;

i) Directly from GPs following a comprehensive assessment.
ii) On discharge from hospital to reduce the risk of a hospital re-admission.

In response to COVID-19 there was a requirement to address unmet need and improve access to specialist care in the home, which resulted in the testing of the community pathway of care as part of the POC. This is in line with and supports Sláintecare in delivering care closer to home and offers an alternative to acute hospital care. However, of note during the period of testing a number of patients were admitted to the CVW on discharge from hospital, to support the transition from hospital to community.

Timely access to specialist advice and care was central to the test supported by remote monitoring in the home without the requirement to present to an acute hospital. This was in addition to specialist generalist care provided by the Community Intervention Team (CIT) and sharing information with the acute hospital. The use of technology supporting the model has been evaluated, inclusive of the level of direct face-to-face care required.

The approach to technology has been reviewed and defined as ***Low Technology*** and ***High Technology***. Low technology is considered technology which is designed to be as simple as possible. High technology is a term that incorporates advanced features.

The low-technology approach was defined as the;

i) ***Provision of electronic devices and direction on use at specified times, remote consultations either via telephone or video.***

The high-technology approach was defined as the;

ii) ***Use of a smart phone or tablet with a self-managed patient portal and blue-tooth remote monitoring devices.***

Spirometry devices were used as part of both low and high technology approaches to measure airflow into and out of the patient's lungs.

The technology was evaluated as part of the POC and was inclusive of self-management (the ability to control and regulate thoughts and use knowledge and skills to problem solving and responding appropriately depending on the condition or illness), symptoms, quality of life and patient experience. The processes of care and level of direct and indirect care provided, enabled by technology, has also been evaluated.

The evaluation of the model including outputs and impact are presented in the Model Delivery chapter of this report.

2.0 | Service Delivery Context

This chapter sets the context to service delivery and delivery of integrated care reviewing hospital at home approaches including the CVW model, as well as telehealth enabled care, such as video-enabled visits and remote monitoring.

Population Changes and Healthcare Reform

Ireland's population is rising and is projected to grow by 10% - 18% between 2016 and 2031, which represents an increase of 481,000 - 875,000 people (Department of Health, 2018a). Additionally, the population aged 65 and over is projected to increase by 59% in this period, while the number of people aged 85 and over is estimated to increase by 97% (Central Statistics Office, 2018). The risk of co-morbidity increases with advancing age with reports that globally, approximately one in three adults suffer from multiple chronic conditions (Hajat and Stein, 2018). This challenges the healthcare system with greater complexity of care needs for the general population (Hajat and Stein, 2018). Outcomes from this are a higher burden of disability and illness, higher risk of caregiver burnout, poor quality of life and difficulties in supporting self-management including medication adherence (Hajat and Stein, 2018). This increases the demand for resources and healthcare spending, with a greater need for specialist support, and higher incidence of emergency department presentations and unplanned hospital admissions (Hajat and Stein, 2018). To respond to this, healthcare reform and service re-design are key objectives within Ireland, with the introduction of Sláintecare to deliver a whole-system approach including policy, strategy, operations and financial investment (Oireachtas, 2017). The main aims of Sláintecare are to provide universal healthcare coverage with access to timely, quality integrated care for everyone in Ireland (Oireachtas, 2017). A key objective of Sláintecare is to develop models that enable services to integrate and provide an environment for eHealth (eHealth refers to health services and the information delivered or enhanced through technologies). This will promote lasting and sustained reform that provides value for money whilst not compromising on quality.

Hospital at home approaches to care

Demographic changes influenced by an increasing age profile, and the prevalence of co-morbidities are challenging the provision of sustainable healthcare in acute hospital settings (Sheppard et al., 2016). Advancing age can increase the demand for acute hospital beds, with over half of all acute hospital admissions are for people over the age of 65 years (Department of Health, 2018). This has resulted in higher risk of hospital acquired infections, longer length of stay and increase in dependency levels (Covinsky et al., 2011). This has informed a discernible shift in care delivery models to support people at home and avoid unnecessary hospital care (Sheppard et al., 2016). Admission avoidance, with care provided in the patient's home that emulates the level of monitoring and care received in hospital with defined escalation pathways, offer an effective alternative to an acute hospital admission (Sheppard et al., 2016). Hospital at home models of care aim to provide case management approaches which involve a co-ordinated, multidisciplinary response to care in their own homes for people who were at a high risk of a hospital admission (Sheppard et al., 2016). There are two common pathways to access this type of care;

i) Those referred by their GP following a primary care assessment.
ii) People either presenting to the Emergency Department (ED) or following discharge from hospital who are considered at risk of a hospital re-admission.

Models can be tailored to individual care needs and reflect the infrastructure within the healthcare setting. Over the last decade the development of Community Virtual Wards (CVW) has provided the model of care to operate hospital at home type approaches. These provide a case-management model and are effective to provide an environment for integration of care and self-management (Leung et al., 2015, Lewis et al., 2017).

Community Virtual Wards Croydon Primary Care Trust

A CVW is most commonly accessible to those at risk of fragmented care and adverse healthcare outcomes, such as advancement in chronic illness (Lewis et al., 2013). Originally developed in the UK in Croydon primary care trust in South London, the model has since been developed in other parts of the UK and in several countries such as Canada, Hong-Kong, and Ireland. The CVW provides a cohesive approach to case management, with a focus on early identification of risk, anticipatory care planning and improved decision-making to promote and plan safer discharges back to usual care, avoiding deterioration and hospital admission (Lewis et al., 2013, Dhalla and O'Brien, 2014, Leung et al., 2015, Lewis et al., 2020).

There are several examples of the delivery of a CVW model that have been tailored to respond to the target population.

COVID Virtual Ward (COVID Care at Home)

COVID virtual wards have been set up and developed in the UK (Tees-Valley) in response to the pandemic (Stockely, 2020). These virtual wards were for patients who had tested positive for COVID-19 with respiratory symptoms and at risk of deterioration in the community and to facilitate discharge from hospital. The COVID virtual ward model delivered enhanced care in the community, inclusive of remote monitoring and remote monitoring devices within a patient's own home (or usual residence). Clinical oversight is provided by the Clinical Commissioning Group and three GP federations in collaboration with three Acute Hospital Trusts. The COVID virtual wards operate out of a Covid Hot Clinic based in the community. The COVID Hot Clinic is operated by GPs and Nurses to support GP practice and divert assessment of symptoms of COVID-19 to a local hub. Patients are referred via the Hot Clinic and from the acute hospital and monitored for a period of 14 days. Virtual ward staff have an agreed escalation pathway to the acute hospital COVID assessment unit, and a pathway to the ambulance service. The ambulance service reviews patients at home as part of welfare checks and provide direct ambulance conveyance from the patient's home to the COVID acute hospital assessment unit.

Patients suitable for admission to the COVID virtual ward collect a remote monitoring oxygen saturation device at a local central point of contact. Follow up care is provided remotely and includes information on management and plan of care and access to non-clinical services during admission. Patients have access to a portal to report readings generated from remote monitoring devices via the my mhealth App. Nursing teams based in the Hot Clinics support those who are unable to access the App or have difficulty inputting their readings. The COVID virtual ward digital dashboard is accessible to staff operating in Hot Clinics, where they can view patients' symptoms and the results recorded (Stockley, 2020).

The COVID virtual ward focuses on early intervention responding to signs of deterioration based on oxygen saturation levels. The main aim is to reduce complications associated with COVID-19, and to reduce need for hospitalisation and intensive care admission (Stockley, 2020).

Early evidence from this type of approach to care in managing COVID has demonstrated a low mortality rate of 1% following approximately 2000 admissions across eight sites (Stockley, 2020). Evidence from the development and scale-up of the COVID virtual wards showed that this enabled the development of

integrated care and aligned pathways of care between community and hospital (Stockley, 2020).

A Community Virtual Ward for Older Persons

A CVW for older persons has been tested as part of a research study in North Dublin (Lewis et al., 2017, Lewis et al., 2020). This CVW admitted patients over 65 years of age (average age 82 years) with signs of frailty and two or more chronic diseases, with evidence of clinical and/or functional deterioration. The programme of care was delivered in the home and involved direct and indirect care delivered by nursing and allied health professionals, such as physiotherapists and occupational therapists. The direct interventions delivered in the home included assessment and delivery of complex care interventions. Examples of interventions delivered were administration of sub-cutaneous fluids, intravenous anti-biotic therapy, management of delirium, end of life care and re-enablement programmes. Evidence from the pilot CVW demonstrated an 87% reduction in ED presentations for the same episode of illness (readmission) for the identified cohort of patients. There was also an 81% reduction in bed days used for the period (Lewis et al., 2017). The care delivered in the CVW, compared to an acute hospital admission or long-term care, was 50% more cost-effective. The cost saving for the 12-month period was €3,115.200. There was also evidence of shorter hospital length of stay (LOS) for patients requiring a planned admission from the CVW to the acute hospital as part of an escalation pathway. The average LOS for planned admissions via the CVW was 15 days versus greater than 60 days as an unplanned hospital admission.

Community Virtual Ward Chronic Disease Management

In Hong-Kong a CVW was developed to facilitate early discharge from the acute hospital. The CVW was integrated with the acute hospital and community working across two nursing teams: i) based in the acute hospital and ii) based in the community. The CVW was supported by a nurse practitioner working across hospital and community and overseen by a consultant geriatrician. The acute hospital team identified suitable patients, undertook early assessments in preparation for discharge and plan of care was arranged with the community team. The community team provided direct care in the home and had direct access to the acute hospital team with escalation pathways to ambulatory care if required. Evidence from this CVW approach demonstrated reduction in ED presentations and improvements in quality of life and self-management efficacy (Leung et al., 2015).

Community Virtual Ward Midlothian Trust

The CVW developed by Midlothian Trust in Scotland provided a community focused approach, supporting networks of GP practices to support people assessed by their GP with evidence of deterioration. The CVW was operated by a rapid response team including advanced nurse practitioners and district nurses overseen by a community geriatrician, with rapid access to community psychiatry and occupational therapists and physiotherapists (Baker and Oliver, 2016). To avoid hospital admissions, patients admitted to the CVW had access to social care beds in the community that provided closer monitoring and rehabilitation for shorter periods in comparison to a hospital admission (Baker and Oliver., 2016). Through a process of case management, the model focused on self-management strategies and management of chronic disease. Results showed a reduction in hospital admissions and evidence of admission avoidance as well as reports of greater integration and improved quality of life by patients (Baker and Oliver, 2016).

Community Virtual Ward Model Summary

There are several approaches to delivering a CVW. Each are unique to the population and can flex around

services or respond to emerging care needs, such as the COVID virtual wards. The key principles of the CVW focus on governance and responsibility in terms of management, good co-ordination of care, access to timely services and a pathway to the acute hospital or other step-up facility to avoid the need for an ED attendance or unplanned hospital admission.

As demonstrated in the COVID virtual wards, technology enabled models of care are transforming how we deliver care to patients and families in the community and support healthcare professionals in their role. As CVW models evolve, it will be essential to incorporate telehealth approaches to improve access and choice and to encourage self-management with greater patient engagement.

Telehealth and Technology Enabled Care

Technology enabled care is referred to as telehealth, telecare, telemedicine and telecoaching (Leonardsen et al., 2020). It aims to engage patients with their own health and has been effective in supporting people with chronic illness. These approaches to care are considered more convenient, accessible, and cost effective. More recently, ***consumer-directed telehealth*** has gained focus as a means not only to supplement traditional healthcare, but also to empower patients by providing them with information and tools to manage their condition (Norman, 2011). The intention of consumer directed telehealth is to provide a healthcare environment in which patients can access care via telephone or videoconferencing using their smartphone, tablet, or laptop. Consumer directed telehealth can also have a wider impact on the consumer (patient), by improving their health knowledge and influencing their behaviour and skills. Since the introduction of the term in 2003, it has been recognised as a potential means to rectify disparities in affecting healthcare caused by distance, cost, and universal healthcare coverage (Norman, 2011). The COVID-19 pandemic has provided an opportunity to implement telehealth approaches at a rapid pace and in an unprecedented scale to alleviate difficulties in accessing traditional healthcare. It has been used in both community healthcare and acute hospital settings, often as a result of collaboration between the two areas, with peer-to-peer networking being especially valuable.

In terms of the delivery telehealth this can be divided into three main categories: ***standalone, complementary and integrated;***

i) **A standalone service** is designed to operate independently of any other resources. Examples of such service can include websites providing health-related information or a text-message service.
ii) **A complementary service** is provided in conjunction with another service, often developed as an ancillary service to a wider health-related media campaign or to a standalone telehealth service. The use of complementary services widens the target group of the campaign/service by using different platforms to reach the customers.
iii) **An integrated telehealth service** is an integral part of the existing programme and therefore requires a significantly higher level of planning and coordination to ensure effective management of all services included in the project.

Common uses of telehealth include:

i) Videoconferencing between a patient and health care provider.
ii) Group videoconferencing between patients or healthcare providers for education, support, and care coordination.
iii) Transmission of data, such as x-rays, photographs, video, and audio files.
iv) Remote monitoring of vital signs and other health indicators.
v) Internet applications for patient education and disease management.

By using these approaches the benefits are fourfold: they reduce physical examinations and hospital admissions, improve coordination of care between community and acute sectors and improve access to patient education supported by video demonstrations (Shigekawa et al., 2018). They also allow for physical

distancing while providing care in the comfort of the patient's home.

Evidence is increasing showing that adoption of telehealth and virtual remote monitoring platforms assists in:

i) *Decreasing the time required in establishing a diagnosis and initiating treatment.*
ii) *Supporting patients to reach a level of stability and reduce the need for an acute hospital admission.*
iii) *Facilitating close follow-up with patients who can be monitored from their home.*
iv) *Co-ordinating medical resources utilized in distant locations.*
v) *Reducing the length of hospital stays.*
vi) *Reducing the number of ED presentations.*
vii) *Stronger engagement of patients in their care plan.*
viii) *Improving access to care for patients with unique challenges or in situations making it difficult to travel to receive traditional care.*
ix) *Increase the numbers of patient who can be treated at the same time.*

Benefits in Utilising Telehealth

The widespread use of telehealth from the onset of COVID-19 has highlighted that a significant proportion of outpatient visits can take place remotely without compromising the quality of care. Telehealth can be implemented rapidly, offering alternative logistic solutions to care delivery and service planning (Uz Zaman and Ali, 2015). It may also facilitate solutions to enhance rapid changes in healthcare capacity (Scott et al., 2020). It can also be an effective tool to triage patients at the first point of contact to ensure a more efficient use of resources within the health system (Odeh et al., 2015). In general, the transition over to telehealth approaches has met with little resistance from patients and healthcare staff and has been generally considered a convenient solution for the current situation (Scott et al., 2020).

Evidence suggests that the use of technologies results in many positive outcomes, including fewer hospital re-admissions, greater adherence, and engagement in prescribed courses of treatment and faster recovery (Uz Zaman and Ali, 2015). Technology enabled care can also support egress from the acute hospital by monitoring discharged patients and tracking patient recovery. It is also an effective way to facilitate communication between patients and healthcare professionals (Uz Zaman and Ali, 2015).

Examples of Telehealth Models

There are a variety of ways to deliver telehealth monitoring dependent on the target population and service requirements. Most commonly it is a combination of virtual consultations and the use of remote monitoring, and remote monitoring devices with information recorded in a digital platform.

Telehealth Outreach Service

In America, universities such as University of Maryland are developing healthcare models which are delivering care differently in both acute hospital and community settings.

In the University of Maryland, a digital platform is providing remote monitoring to support patients on wards during night-time periods as part of outreach from intensive care units (Shigekawa et al., 2018). This is overseen by critical care nursing teams and supported by medical teams and consultants (Shigekawaet al., 2018). The same remote monitoring digital platform has been developed to provide home-based remote monitoring, to support patients with chronic disease management and detect for early deterioration to reduce need for acute hospital care.

The governance of these models is under the acute hospital, with support delivered by community services. This was to ensure that patients had access to prompt acute care if evidence of deterioration and to a 7/7 service inclusive of out-of-hours. The home-based remote monitoring model is overseen by consultants working in areas of stroke care, high-risk prenatal medicine, psychiatry, and genetics counselling. The

remote monitoring programmes are offered to patients with cerebral vascular disease or injury, advanced liver disease and inflammatory bowel disease.

Other telehealth programmes which has transformed screening and primary care delivery has been developed by Johns Hopkins Medicine (Siwicki, 2020). In the ambulatory space, Johns Hopkins Medicine has completed more than 400,000 virtual visits, providing care to approximately 200,000 patients. Ambulatory care generally refers to the healthcare sector which provides outpatient services in primary care, university, and regional hospitals to include clinics, emergency departments and telehealth services (Rapin et al., 2015).

The ambulatory care programmes were enabled by telehealth offering services to school health clinics. This offered a more convenient and economical alternative to in-person visits to enable early diagnosis and expert medical follow-up, and to help patients stay independent. This approach has been expanded to screening for diabetic retinopathy, respiratory and Parkinson's disease management. Employing virtual touchpoints of care using remote monitoring, remote monitoring devices and video enabled consultations demonstrated that this model of care created a safe environment after acute illness. A total of 270 patients were enrolled onto the home pulse oximetry programme, with only around 2% requiring a hospital readmission (Siwicki, 2020). The governance structure adopted for these models was seen to influence the low re-admission rates provided by the acute hospital working with community and primary care services at home (Siwicki, 2020). Therefore, rapid acute care pathways could be escalated and timely access to diagnostics and specialist interventions was ensured.

Telehealth for Chronic Disease Management

In Norway, a telehealth programme for neurology combined remote monitoring, use of remote monitoring devices and virtual consultations. The outcomes of the programme showed a reduction in the number of headaches experienced and greater satisfaction in terms of care delivery and access when compared to in-person appointments. Patients and caregivers cited the convenience of decreased travel times and costs as the main drivers for satisfaction with remote care (Müller, 2017).

These positive experiences by patients and families have been reported during the COVID-19 pandemic, with one study demonstrating that 89% of patients accessing remote care for chronic care management were more than satisfied with this type of approach to care than in-person visits (Mustafa et al., 2020). The virtual care benefits included less time away from school and work, a decrease in wait times, and increased access to see specialist teams (Mustafa et al., 2020). Feedback from other studies examining the impact of remote monitoring showed that nearly 50% of patients accessing this type of care felt more supported (Odeh et al., 2015). Patients reported that without it they would more likely have required urgent care or may not have acted on symptoms as quickly, resulting in unnecessary ED presentations (Odeh et al., 2015).

Telehealth for Older Persons Care

In Ireland, telehealth is supporting older persons to live at home. A model in Dublin North Central, referred to as the Geriatrician Led Assisted Discharge (GLAD) project, provides remote monitoring to support people leaving hospital or a step-down facility or in a residential care setting. The model is overseen by a specialist geriatric team including a geriatrician, clinical nurse specialist, advanced nurse practitioner, physiotherapist and occupational therapist (Power, 2020).

The clinical governance of the model is with the acute hospital led by the consultant geriatrician and supports community care as part of admission avoidance or hospital re-admission. The team operate out of a step-down facility attached to the acute hospital. The target population is older persons with acute but stable exacerbations of chronic illness and/or recent fall, requiring support on discharge from hospital.

Patients receive a hospital-at-home type approach to care and are also remotely monitored using remote monitoring devices to measure blood pressure, pulse, weight, and symptom assessment either daily or twice weekly. Socio-technical support (Socio-technical support is considered as the provision of education and technical training to patients on use of telehealth approaches to care, and how this links with self-management) is provided by the team with the use of the technology. Data generated from remote monitoring devices are sent to an IT platform that is readily accessible to healthcare staff within the step-down unit providing real time information. Data is recorded by care staff, family members and in some instances by the patient themselves and reviewed twice daily by the lead geriatrician and team (at 8am with the nursing and junior medical staff at a virtual ward round, and at 5pm with a physician only review). New treatments and/or assessments are requested via the IT platform or communicated directly by phone if the clinical scenario demands that level of urgency.

As part of the GLAD project, the model was tested in one residential care area located in the catchment area of the acute hospital. The consultant geriatrician and the clinical nurse specialist in gerontology reviewed residents with evidence of deterioration and assessed suitability for remote monitoring. The team within the step-down facility admitted patients onto the digital platform and provided remote monitoring devices to support the facility nurse manager to continue to care for the residents. Technical support was provided to the residential care manager. Remote monitoring data was reviewed by nurses and medical staff in the remote monitoring hub within the step-down unit twice daily and prioritised.

Results from the GLAD project have shown shorter lengths of stay, achieving discharge at 17-days, and reduced re-admissions as well as potential residential care admission avoidances.

Limitations in the use of Telehealth

There are several limitations in using telehealth approaches to care delivery. These include;

i. Inability to assess patients face-to-face, this includes direct physical assessment and review of personal holistic health care needs (Mustafa et al., 2020).
ii. Patient's ability to access and use the technology without formal or informal support and lack of clarity on instructions and level of support required (Vaporsis et al., 2017).
iii. Security of personal data and transmission of information electronically (Ronco et al., 2019).
iv. Governance of patient care based on remote monitoring data (if patient deteriorates who has responsibility to provide timely interventions and escalate appropriately) (Siwicki, 2020).
v. Limited access to equipment and smart phone/ laptop devices for both patients and staff (Skeet et al., 2019).
vi. Education of technology for patients, families, and staff (Diaz-Skeete et al., 2019).

Addressing Limitations of Telehealth

To address the limitations of telehealth, evidence suggests that the development of models that deliver a combination of remote monitoring and direct face-to face care is required (Power, 2020). Providing alternative low technology approaches in addition to socio-technology supports can avoid telehealth and digital alienation in groups of populations (Stockley, 2020). Having clear governance structures to define accountability and the roles and responsibilities as part of remote monitoring programmes ensure patient safety is maintained (Shigekawa et al., 2018). This includes triggers for escalation pathways to appropriate care settings (for example the acute hospital). As part of data protection and security, remote monitoring programmes must ensure that there are processes in place, that include patient consent to share information, and the infrastructure to record and share information is secure to reflect legislative and regulatory requirements (Ronco et al., 2019). To improve usability, it is necessary to design systems to support remote monitoring approaches that are user friendly for patients, families and staff with agile education as technological approaches advance (Diaz-Skeete et al., 2019).

Telehealth Summary

Telehealth approaches to care delivery are transforming how patients can access and engage with health and social care services. This includes access to specialist care delivered by the acute hospital and the community to patients in their own homes using remote monitoring, including video or telephone consultation. The benefits of this approach are clear - it reduces the need for unnecessary hospital visits, improves access to healthcare services provided in the local community, and reduces both the risk of infection and the time and expense associated with travel to an acute hospital or specialist centre. However, to provide a person-centred holistic approach to care, it is important to develop flexibility to adopt both telehealth and direct face-to-face care as required.

Conclusion

Hospital at home approaches delivered using a CVW approach have proven to be safe, effective, and efficient. These are agile models that can flex around services and evolve to meet the needs of the population or respond to situations (for example COVID-19, hospital capacity issues). They also provide an environment for integration between hospital and community, and an alternative to an acute hospital admission. To enable this, Virtual Ward models are expanding, adopting telehealth approaches such as remote monitoring using remote monitoring devices to support patients at home, with great success. Therefore, developing a CVW that is enabled by telehealth using remote care and providing direct face-to-face care as required will assist in improving access and coverage and greater patient engagement.

3.0 | Testing of a Proof of Concept Community Virtual Ward

This chapter outlines the CVW model of care that was planned and tested in one site that included an acute hospital (Beaumont University Hospital) and community healthcare organisation (CHO 9 Dublin North Central and County). The key pillars of the model tested included the governance structure, integration of services and the processes of care (inclusive of remote monitoring). The outputs (face-to-face care, video enabled care and telephone support) and outcomes (patient self-efficacy, symptoms, quality of life) of the model are presented in this chapter. The strategic approach underpinning the test has assisted in determining the governance of the model, the resources and the level of integration of care required, and how technology can be leveraged to promote patient engagement. The patient and staff experience are presented, as well as the key metrics to assess performance. The model of care was developed incorporating the evidence and best practice presented in Chapter two.

The CVW was tested as part of the Implementation Plan for the EN role to facilitate a shift in practice to the community. The EN role provides an opportunity to act as an enabler in the delivery of Sláintecare and to transform the nursing and midwifery professions.

A CVW was tested as a proof of concept (POC) to examine a model of care that will support ENs to work to the top of their licence and create opportunities to deliver care differently. The POC test assisted in examining design and functionality of the model before entering larger-scale pilot testing.

The overall aim of the CVW POC was **to provide;**

i) ***Short-term care (11 - 14 days) with enhanced community monitoring and interventions to reverse a sub-acute event and/or reduce the number of exacerbations or risk of an unplanned hospital admission.***

The programme of care focused on intensive symptom and disease management and care co-ordination using a case management approach.

As part of the implementation plan for the Labour Court Recommendations (LCR21900) and testing the CVW, there were **two deliverables;**

i) ***To identify one pilot site (acute hospital and community) to test a Community Virtual Ward.***
ii) ***To assess results of pilot and develop rollout plan to extend community virtual wards to other sites as appropriate.***

To assess results of the pilot and develop a rollout plan to expand in the community to other sites as appropriate**.** The objectives were;

i) ***To test the delivery of acute hospital nursing services directly in the community working with a nurse-led community intervention team.***
ii) ***To test the CVW model to include a combination of remote monitoring and direct care in the community to support patients at home.***

Target Population

The target population selected to test the POC CVW was for those living with COPD and/or Asthma. Selecting this population was informed by a review of national data demonstrating that COPD was the top medical discharge in Ireland in 2018, with respiratory conditions remaining in the top 5 acute hospital discharge conditions for 2019 (Figure. 1 & 2).

Model Delivery

The model tested integration of care with one CHO and an acute hospital that were geographically aligned. The test ran for 12 weeks and ran between August and November 2020. This time-period was chosen to allow for sufficient time to identify any barriers or challenges and provide solutions. The model was delivered collaboratively, through a clinical governance

Figure. 1 Medical Discharges Acute Hospitals 2018

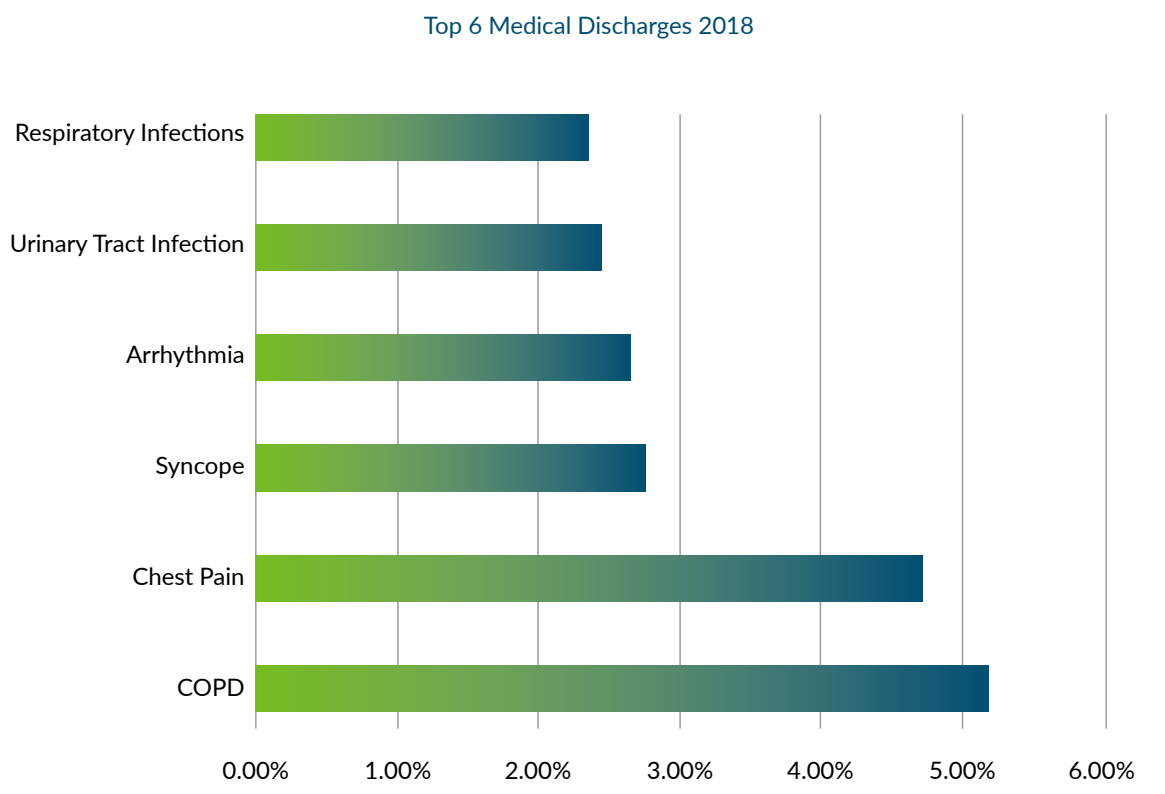
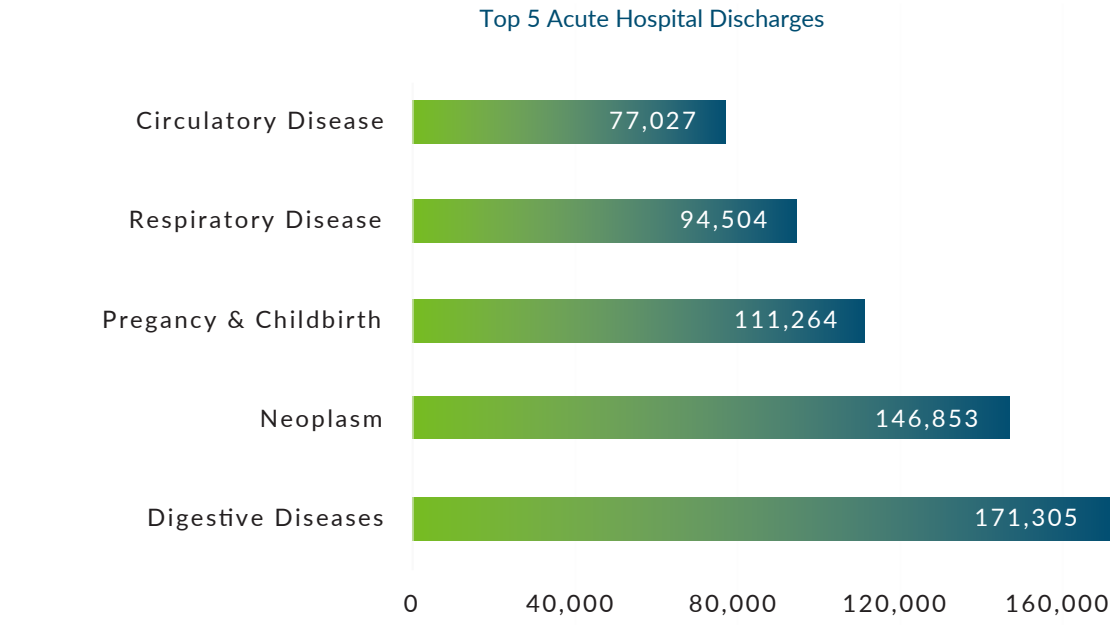


Figure. 2 Medical Discharges Acute Hospitals 2019



group including specialist respiratory nursing services and a community nursing service from the Community Intervention Team (CIT).

The POC tested the community pathway for patients referred from GPs. The community pathway was tested as part of a COVID-19 response to assist in addressing unmet need for people living with chronic respiratory conditions and offer access to care in the home.

Establishing a Clinical Governance Group

A clinical governance group was established with membership from CHO 9 DNCC, Beaumont University Hospital, the Chief Nursing Officer's Office and Office of the Nursing and Midwifery Services Director. The group informed the planning, implementation, and evaluation of the POC. Members of the group included leads in operational services at CHO and acute hospital level, nursing management from both the acute hospital and community, GP lead, consultants and advanced nurse practitioners from respiratory services, nursing leads from the Chief Nursing Officer's Office and Office of Nursing and Midwifery Services in acute/community, digital healthcare, education, training, and public health. This was in addition to technology leads for the remote monitoring platform. The group provided knowledge, expertise, and leadership in translating the evidence into practice that reflected the infrastructure available to operate a CVW safely.

There were several critical steps required supported by the clinical governance group as part of the CVW planning, implementation, and evaluation. **This included;**

- The development of a governance structure to oversee the CVW.
- Referral documentation and criteria for referral.
- Define the processes and pathways of care including triggers to indicate deterioration.
- Define and develop an escalation pathway to the acute hospital as required.
- Identify outpatient ambulatory care pathway as part of the programme of care.
- Define and develop the pathway for out-of-hours support for patients and staff.

- The training needs and support for staff in the use of remote monitoring (including logistics for delivery and collection of remote monitoring devices to patients).
- Equipment and training required for the digital and electronic recording of patient care.
- The technical support for patients in setting up remote monitoring on smart devices.
- Data protection and sharing of information across hospital and community.
- Develop a minimum data set as part of evaluation and agree upon screening tools to measure patient related outcome measures.

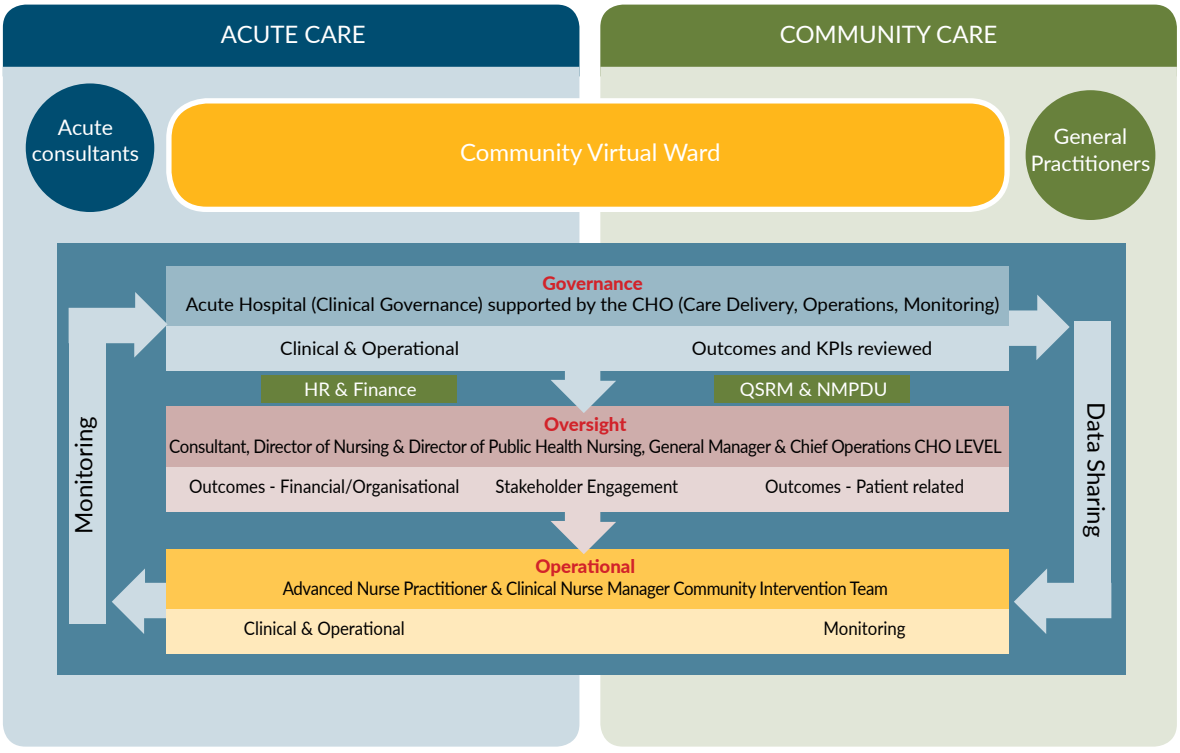
The clinical governance group met regularly (approximately every 1-2 weeks) as the POC CVW was evolving in the context of a pandemic. Therefore, the group reviewed the current pandemic situation and impact on CVW progress to identify any barriers or challenges and provide solutions.

The Community Virtual Ward Clinical Governance Structure

The clinical governance for the CVW POC was under the acute hospital and supported by the CHO in terms of care delivery, resources, monitoring and data sharing (Figure 3). This was determined the safest approach to patient care based on review of the evidence, to ensure that there were timely escalation pathways to the acute hospital and to share information and outcomes across hospital and community, as well as providing a step-up approach to care in the community to care delivered in the patient's home.

Acute hospital governance was determined to be the safest approach to support the CVW given the level of care required for patients with complex respiratory care needs during a sub-acute event. It is in this type of high-risk patient-population that an expert blend

Figure. 3 Governance approach to the Community Virtual Ward



of acute hospital and community care is required, to ensure symptoms are assessed appropriately, care plans are safe and effective, and that the patient is recieving care in the right place.

The governance structure supports the higher level of enhanced monitoring required than normally observed in primary care or community specialist teams. This includes escalation pathways that are based on a combination of real-time objective data, with timely intervention across a 7-day and out-of-hours service. Although the clinical governance was under the acute hospital, the delivery of care was collaborative with Advanced Nurse Practitioners based in the acute hospital and community nurses (inclusive of ENs) based in the CIT service. Therefore, the nursing and professional governance was shared between the acute hospital and community. Once patients were discharged from the CVW, the clinical governance was transferred to the GP with support provided by various members of the primary care team (for example the Public Health Nurse, Occupational Therapist, Physiotherapist, Social Worker, Pharmacist) and community services (Community Chronic Disease Management Programme, ALONE) as required.

Evaluation of the Community Virtual Ward Governance Structure

The governance approach supported the CVW has been successful in providing quality of care whilst maintaining patient safety. There were no reported patient safety issues or events, patients were supported at home and received planned and timely access to ambulatory outpatient care and diagnostics. CVW ward rounds operated daily with acute hospital oversight and input and collaboration with CIT.

The success of the governance approach was also reported by the consultants overseeing the CVW, Advanced Nurse Practitioners in the acute hospital and the CIT. This is based on evidence of early intervention to reverse an acute exacerbation, timely escalation to ambulatory care, evidence of reaching a level of stability with treatment interventions, objective data and symptoms reported by patients.

The success to deliver safe care was the combined approach to assessment and follow-up utilising the expertise of acute hospital staff and the CIT. It has also provided the opportunity to support community nursing to deliver specialist care in addition to a generalist approach. This ensures that the service delivered is both efficient and effective, and that there are clear lines of clinical responsibility with a defined escalation pathway if a patient is deteriorating.

Resource

The model was tested using existing resources for a defined period of 12 weeks, with a maximum capacity of 20 patients in 20 CVW beds. The CVW beds operated over a 7-day service from 8am-8pm. The CVW was delivered within the current CIT nursing structure based in CHO9 (DNCC), with a co-ordinator working at CNM3 level. The CIT CVW team comprised of a CNM1 and 2-3 Enhanced Nurses per shift providing both remote and direct care. In the acute hospital there were 1-2 Advanced Nurse Practitioners (ANP), operating between 8am-4pm Monday to Friday, and a lead hospital consultant with responsibility for the CVW. The CVW offered a 7/7 24-hour service, with access to out-of-hours services if required in the acute hospital. supported by senior nurses (CNM1 and CNM3 level) and the medical registrar (on-call). There is a CNM3 in the CIT in Dublin North Central and County; this is unique to this area, as they offer infusion therapy outpatient services in addition to interventions within the home requiring a CNM3 grade to manage multiple services. The CNM1 supports the CNM3 operationally with day-day management of staff and patient prioritisation. The medical registrar is the senior doctor who is based in the acute hospital and covers acute out-of-hour respiratory service.

The model was enabled by a remote monitoring platform with capability to share information across the hospital and community, delivered via a patient portal and a hospital portal. The patient portal was used as part of a high-technological approach to care delivery with access to self-directed assessments, educational videos and capacity to Bluetooth recordings from remote monitoring devices uploaded directly to the hospital portal. To receive a high-technology approach, access to a smart phone or tablet was required. The monitoring devices included a saturation monitor and spirometry. Spirometry is a common type of breathing test to measures how much air the patient can breathe in and out of their lungs, as well as how easily and fast they can the blow the air out of their lungs.

Demographics

As part of the test, a total of 20 patients accessed the 20 beds operated in the CVW. These were referred mainly from GPs, expanding referrals to include outpatient services and on discharge from hospital. The average age of those accessing the CVW was 65 years (ranging from 45 to 81 years). The average number of exacerbations for the group was five in the last 12 months, with 2-3 hospital admissions. Multi-morbidity was high, with patients living with three or more co-morbidities and having signs suggestive of frailty. Referral to the CVW was either for an exacerbation of their condition or for self-management due to risks of a hospital admission as approaching the winter months. The referral criteria and pathway are presented in Appendix 1.

Admission criteria and discharge

The admission criteria were developed by the clinical governance group with key triggers indicating deterioration that are commonly observed in respiratory conditions. This assisted in determining suitability for admission to the CVW. The criteria are presented in Appendix 1 and were expanded to include patients that were not acutely symptomatic but were at high risk of an unplanned hospital admission due to the number of previous exacerbations. Determining if suitable for discharge was based on 3 core areas;

i) ***Objective data*** (oxygen levels, spirometry recordings, heart rate, pulse rate, respiratory rate, temperature).
ii) ***Symptoms*** (for example level of breathless, cough, anxiety).
iii) ***Response to treatment plan*** (assessing clinical, social, function, nutrition, behaviour). This included a review of objective data, symptoms, social support to longer-term plan of care and scores recorded in screening tools (self-efficacy, quality of life, symptoms).

Assessment and Screening Tools

Assessments were continuous during admission, starting with an initial pre-assessment at the triage phase to determine suitability for the CVW and at the first point of contact when admitted to the CVW. The first point of contact assessment determined suitability for low technology approaches or high technology approaches, patient history, health status and treatment required during admission. This also assisted with a collaborative approach to care determining level of input by the ANPs and CIT service to support care delivery. Patients received follow-up assessments daily during the admission, either via a video enabled consultation, telephone consultation or face-to-face (in the patient's home). Several screening tools were also utilised as part of initial and ongoing assessments to measure quality of life, self-efficacy, function, level of frailty, dependency level and symptoms (Appendix 3). The screening tools assisted in measuring impact of interventions and inform discharge plans.

Care Delivery

The care delivered focused on sub-acute care (sub-acute care is enhanced care that is designed for someone who is experiencing acute illness, injury or exacerbation of a disease process and is generally more intensive than traditional nursing care), social determinants of care

(home environment, educational care needs, access to healthy food options, social support network, community engagement and healthcare coverage), disease modification (reverse or reduce impact of the illness/injury/disease) and targeting the treatable traits (the clinical, environmental and behavioural factors associated with the chronic illness) (Figure 4). The processes of care (interventions performed during the delivery of patient care) are presented in Table 2.

Method of Care Delivery

The assessment and care delivery were provided either remotely, via video or telephone consultation, or directly (Figure. 5). In total ANPs working in the CVW delivered approximately 85% (Table 1) of their care remotely, with patients requiring on average 5.5 remote contacts and 15% requiring additional direct contact, such as a review in the ambulatory outpatient unit, as part of an escalation pathway. The CIT delivered a higher number of indirect virtual contacts (average 8.9 contacts) versus direct face-to-face contacts (average 3.5 visits) (Table 1). However, all patients had a direct visit on at least three occasions over the duration of the admission, undertaken within the first 24 hours of admission, at the mid-way point of admission and on discharge.

Figure. 4 Core Pillars of Care Delivery

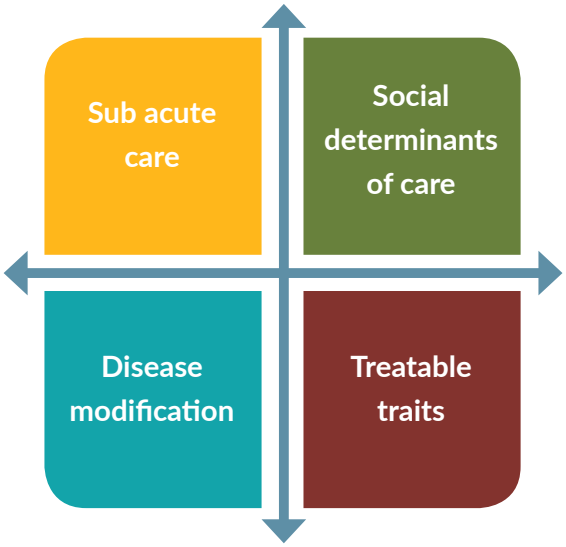


Table 1 Remote, Indirect and Direct Contact Advanced Nurse Practitioners and Community Intervention Team

Contacts	Average contacts remote care per patient	Average Time spent remote care per patient	Average Direct care per patient	Average Time spent per patient	Average Indirect care per patient	Average Time spent per contact indirect care
ANP	5.5	47 mins	0.15	90 mins	7.95	35 mins
CIT	4.25	30 mins	3.4	40 mins	4.25	30 mins

Figure. 5 ANPs and CIT Direct Remote Virtual Consultation and Indirect Contacts

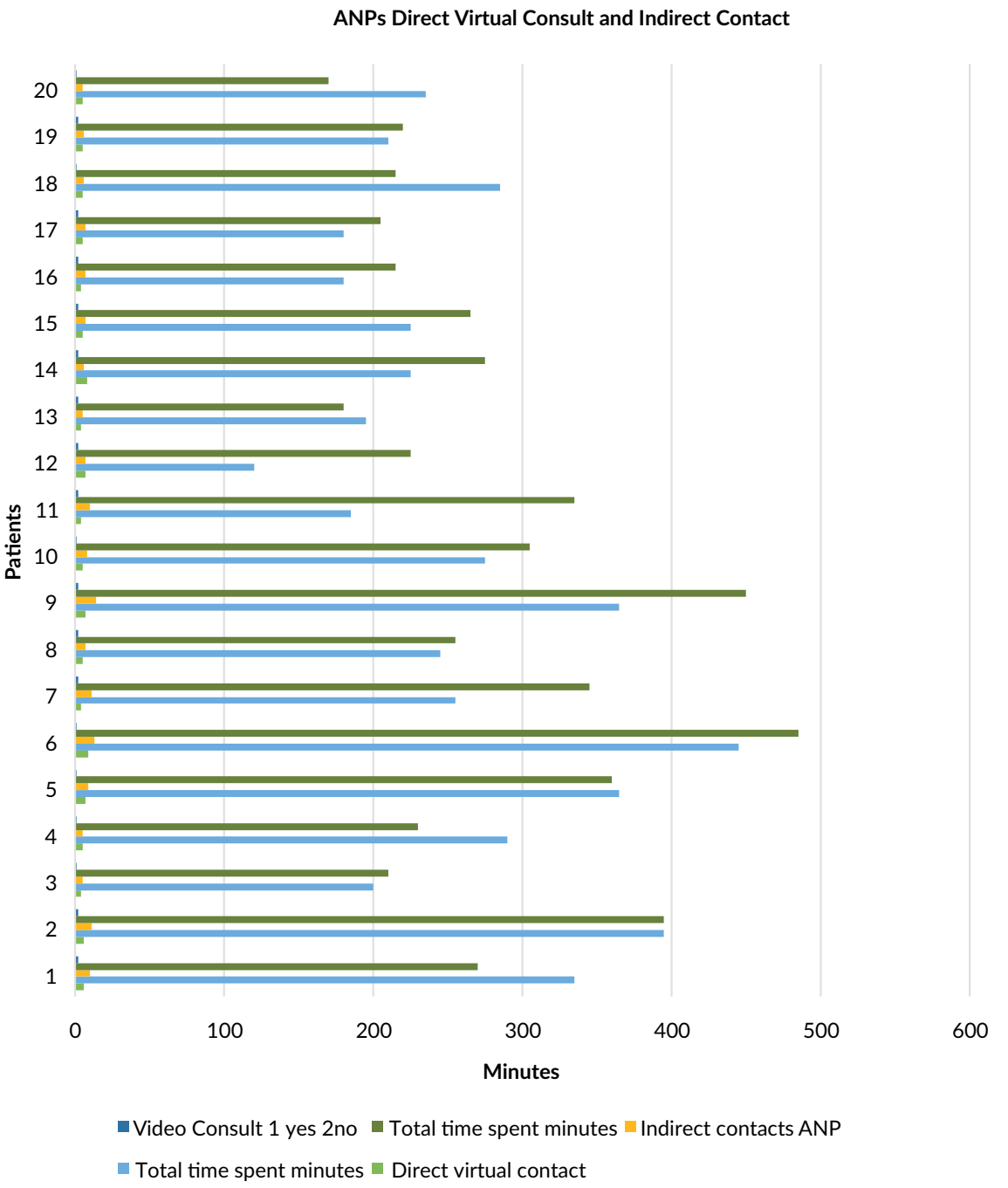


Figure. 5 ANPs and CIT Direct Remote Virtual Consultation and Indirect Contacts

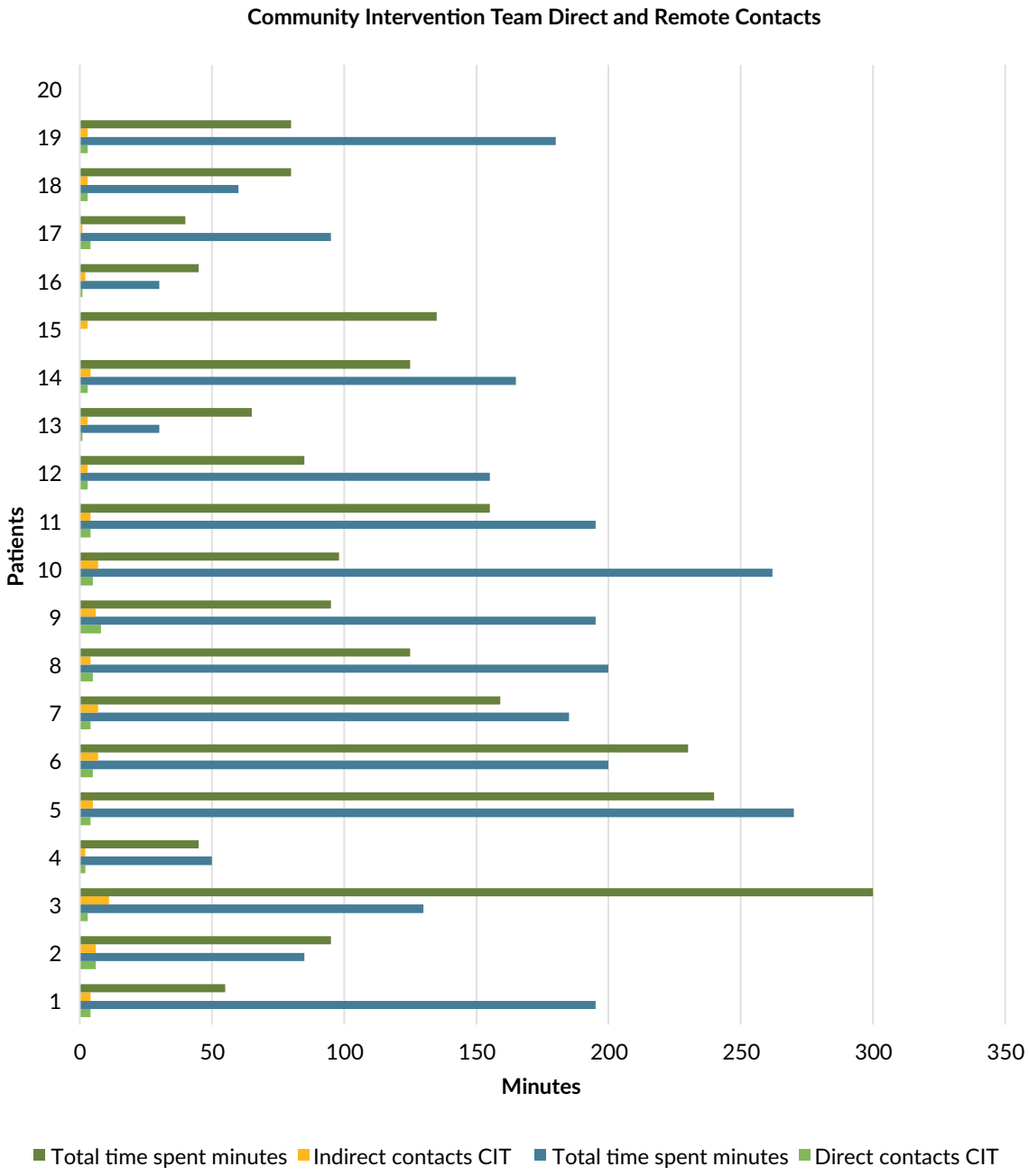


Table 2 Interventions Delivered in the Community Virtual Ward

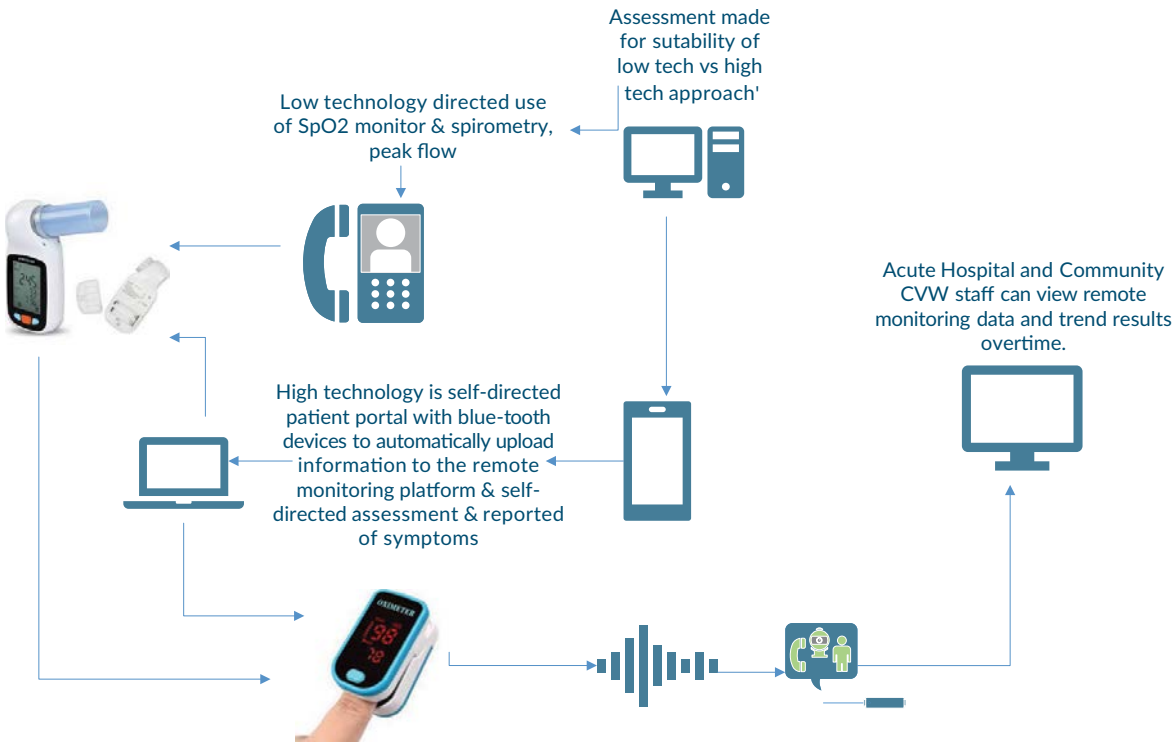
Core Areas Care Delivery	ANP Delivered	CIT Delivered (inclusive of Enhanced Nurse)
Clinical	Advanced Health Assessment to determine suitability for CVW, health status, diagnosis & initial treatment plan Assessment for high-tech or low-tech approach Video and telephone assessment Prescribed treatment pharmacological/no-pharmacological, request diagnostics Determine level of support required by CIT for first stage of admission (1-3 days) Review of diagnostics and treatment plans altered accordingly Nebulized treatment, steroid, antibiotic and oxygen therapy Organise escalation to the acute hospital as required Evaluation of objective data and symptoms Determining suitability discharge from the CVW Discharge to GP and referral onto chronic disease management services	Holistic home assessment of symptoms, medication reconciliation, self-management in the home, home environment (equipment), nutrition, mood, basic cognitive assessment, function, frailty status. Determine feasibility to implement clinical treatment plan in the home. Monitor symptoms and check vital signs, blood pressure, temperature, pulse. Re-assess symptoms and update ANP
Social	Assessment of social supports to facilitate high tech or low-tech approach, delivery of the care plan and determining level of CIT input to support care plan and monitoring	Assessment of home environment, access to home supports for activities of daily living, referral onto to public health nurse if needs exceed current supports
Behavioural	Anxiety management & referral onto specialist and general services	Anxiety management referring to ANP for further input
Functional	Assessment of results of functional screening tool, further assessment inclusive of symptoms	Complete functional screening tool
Nutritional	Review of CIT assessment of weight and height and dietary intake	Assessment of dietary intake and weight, meal preparation and access to food resources
Technical	Support delivery of high-tech-low tech, video enabled assessment, direction on remote monitoring device use, inhaler use and nebulizer use	Education on inhaler technique Review of equipment Training on remote monitoring Device use in the home
Educational	Patient education based on diagnostic results, self-management strategies, non-pharmacological measures & video enabled education	Direct education on symptom recognition, management of symptoms and non-pharmacological measures

Remote technology

The model of care was enabled by a remote monitoring platform and remote monitoring devices (Figure. 6). The remote monitoring devices measured oxygen levels and lung function, with capability to upload information automatically by Bluetooth to the patient and hospital portal. This was accessible with a shared view by clinicians in both hospital and community to review and trend results overtime. Patients without access to a smart phone or tablet were given the remote monitoring devices and provided with direction on times to use. Video enabled assessment was offered to all patients, with nurses reporting that this reduced the need for direct review, as they completed a visual assessment and a virtual physical assessment. This was in addition to facilitating video enabled education and directing treatment plans.

When comparing a higher technological approach with access to a patient portal and Bluetooth operability with devices versus a lower technological approach with access to devices, there was no significant differences in outcomes. This also included patient experience with similar feedback and reports identifying that access to the technology devices assisted in understanding their symptoms, especially in terms of anxiety induced breathlessness.

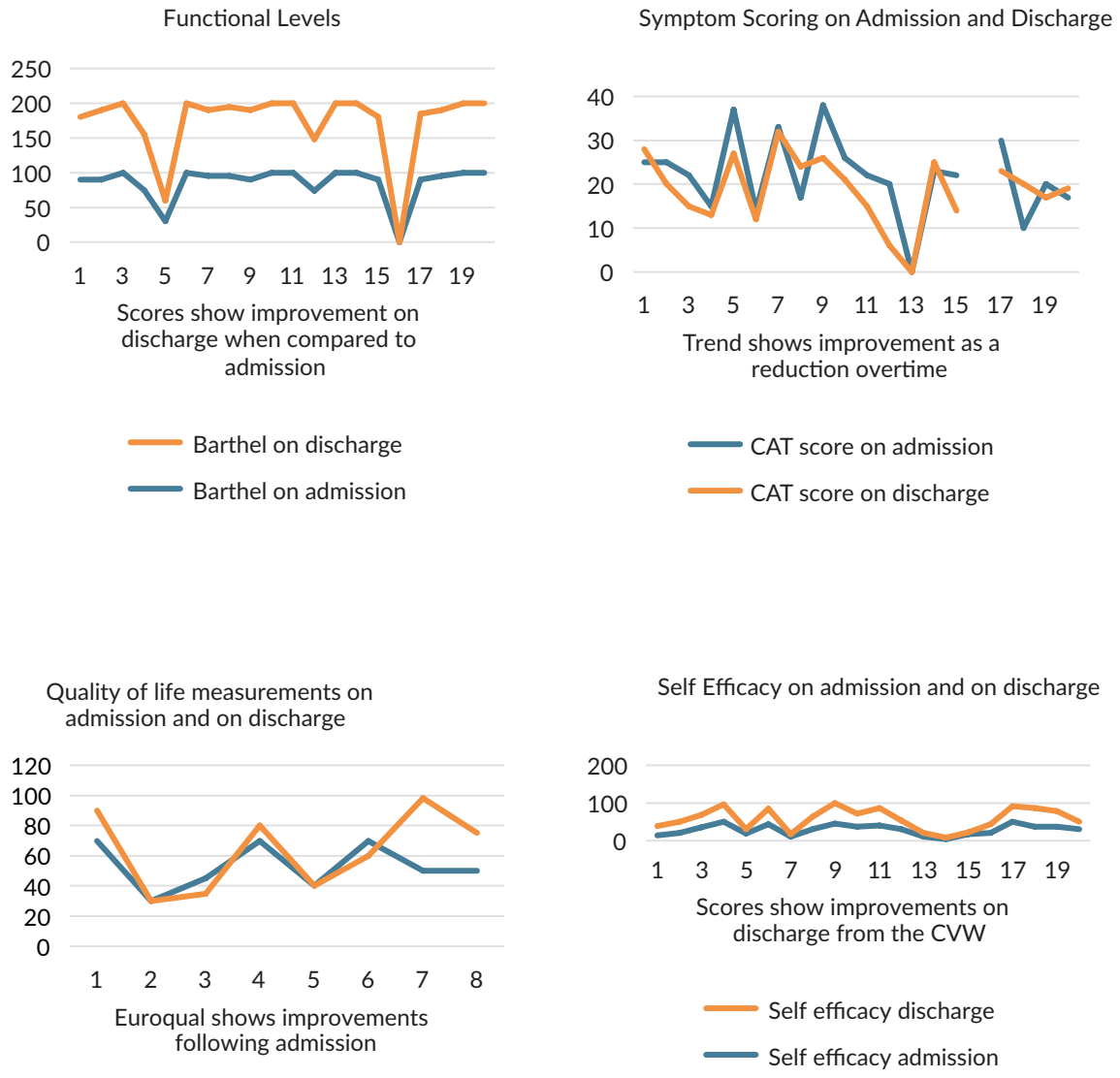
Figure. 6 Remote Technology Approach for the Community Virtual Ward



Response to care delivery in the CVW

To measure response to care delivery, several risk screening tools were used to assess quality of life, frailty status, functional levels, symptoms, and self-efficacy in managing own health on admission and on discharge. There were changes in scores with overall improvements in quality of life, functional level, symptoms and self-efficacy following admission. Scores assessing these areas improved by average of 2-5 points, showing improvement in quality of life, greater understanding, and ability to self-manage in addition to symptom improvement (Figure. 7).

Figure. 7 Screening tools on admission and discharge



Patient Feedback

The patient experience was measured using a modified version of the National Patient Experience Survey. Feedback was obtained at the end of the programme provided at the last visit and was anonymous. The feedback has been broken down into common themes and presented in Table 3. These included;

i) ***Symptom Recognition***
ii) ***Self-Management***
iii) ***Remote Monitoring***
iv) ***Shared Care/Partnership***
v) ***Hospitalisation***

The feedback overall was very positive. Below are excerpts from patients admitted to the CVW:

The setup of the model; *"Very good -very thoughtful and detailed." "I was really delighted to have taken part in this trial, and really hope it can continue, to help people to understand their problems with having asthma". "My husband agreed it was a great service. I would be very happy to be referred to the CVW by the GP in future".*

"Great having monitoring at home"– *great to sleep in my own bed". "Technology very easy to use. I felt safe going home from hospital knowing that I was being monitored and followed up on by telephone.*

Having the equipment to monitor their condition: *3 patients. "I liked having the technology to see my levels and to see how I was doing".*

Table 3 Patient Experience Feedback

Symptom recognition	Someone to talk to about their condition, new information on oxygen use in context of symptoms, understanding what symptoms mean and how to manage or escalate before needing a hospital admission.
Self-management	Great education about nebulisers use, greater understanding of their lung condition and how to manage an exacerbation, knowing what to do to prevent exacerbations as much as possible, knowing what to do when feeling breathless and how to take inhalers. A better understanding of importance of vaccinations, exercise, nutrition, keeping active and smoking cessation.
Remote monitoring	Having access and choice to remote care, being able to be connected with the hospital and community at the same time when feeling unwell particularly with COVID-19. Having technology to monitor symptoms, monitor progress and know that this is being reviewed by nurses and doctors regularly when I am feeling unwell.
Shared care/ partnership	***"Great to be included in my own care."*** Involvement of family members was essential, making them more aware of the condition and support needed.
Hospital	Having contact with the hospital while staying in their own home. Ability to stay out of hospital and still have that expert support from both hospital and community when unwell. Having access to the CVW when leaving hospital to reduce fear and anxiety. Feeling safe going home from hospital knowing that there was that level of monitoring and followed up on by telephone and video call. Choosing the CVW rather than acute hospital admission. Leaving hospital earlier knowing there was access to the CVW.

General Practitioner Feedback

There were four group practices involved in the POC. The main themes were generated from their feedback presented in Table 4;

Clinician Feedback

The feedback from clinicians included community nurses (CIT), ANPs, medical registrars and respiratory consultants involved in the POC. The main themes are presented in Table 5;

Table 4 General Practitioner Feedback & Access to the CVW

Benefits of the model	GPs recognised the value of the CVW model, highlighting its benefits as support to specialist care in the home and its benefits to support high risk and frail patients that can be monitored without the risk and inconvenience of hospital.
Referral process	The GPs indicated that the preparation pack was helpful to understand the model of care and found the referral form user friendly, although they noted that it takes time, which may become more challenging to complete during busier days. They indicated that using Health Link (Digital Referral Process) would significantly improve this.
GP engagement	GPs noted the importance of building up awareness of the model among the GPs to increase access and promotion of the model, i.e. through presentations in Continuing Medical Education (CME) meetings in locality.

Table 5 Clinician Feedback CVW Model

Sharing real-time information	The CVW would not have worked without the capacity to share data electronically. This ensured all patient data and assessments were accessible to both the community and hospital teams in real time. This supported a seamless handover of patients between staff and allowed for staff to take leave and/or support the CVW on a less than full time basis without incident.
Suitable for a variety of indications	The model facilitated the successful testing of various scenarios with a range of acuity including acutely exacerbating patients in the community, post- discharge support, disease optimisation in highly symptomatic patients and supervised complex therapeutic regimes.
Integration with CIT	Integration of care with CIT was invaluable supporting visits to the patients' home, identifying and understanding the barriers which exist to an individual patients' and identifying other factors which can contribute to overall disease burden. This directed the plan of care and level of remote monitoring required.
Equitable access	Having access to direct home and virtual visits allowed for equitable access to the CVW for patients who have in the past had difficulty accessing hospital services for various reasons (such as requires domiciliary care, difficulty accessing transport, caregiver support to attend outpatient services, balancing work and home commitments with appointment schedules).

4.0 | Mapping of Care Delivery Community Virtual Ward

Determining the process of care and complexity associated with this can be challenging. Mapping exercises can assist with this and identify the strengths and potential gaps in service delivery and provide solutions.

The process mapping undertaken was separated into **two stages;**

i) ***How patients are admitted and move through the CVW (Figure. 10).***

ii) ***The movement of information to support triage, decision making, sharing data (Figure. 10).***

The mapping process demonstrated four key areas that supported patient movement through the CVW. This included (Figure. 8);

i) **Collaborative assessment and collaborative care planning** - Referral pathway, triage and admission phase, assessment (inclusive of diagnostics), care plan (inclusive of remote monitoring plan, interventions & core domains of care), progress, logistical requirements to facilitate access and collection of remote monitoring devices, sharing of information, discharge planning (inclusive of referrals) and communication to clinicians on discharge from the CVW.

ii) **Integrated transitions of care acute hospital and community** - Remote monitoring video enabled assessment, telephone assessment/ review, remote monitoring devices, home visits, interventions, review in the ambulatory care unit, referral onwards to acute and community specialist and generalist services.

iii) **Technology Enabled Care** - Telehealth, socio-technical support, video enabled assessment and education, remote device education and symptom recognition.

iv) **Integration of information** - recording and sharing of information in real-time to include: objective data, assessment, care planning interventions, response, discharge plans.

Figure. 8 Core areas to support the CVW as part of process mapping

Sharing of information across services in the acute hospital and community was viewed as a significant strength to the CVW. However, the level of information required and movement of information during admission also highlighted several areas that require consideration as part of the strategic response to scaling of the CVW.

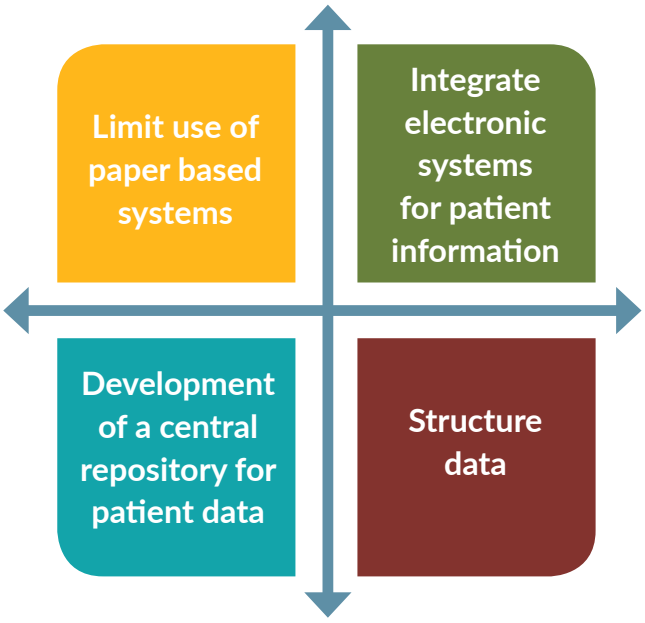
This included (see Table 6, Figure. 9);

i) Paper Based Systems.
ii) Administrative Duplication.
iii) Integration of Systems.
iv) Unstructured Data.

Table 6 Information Movement within the Community Virtual Ward

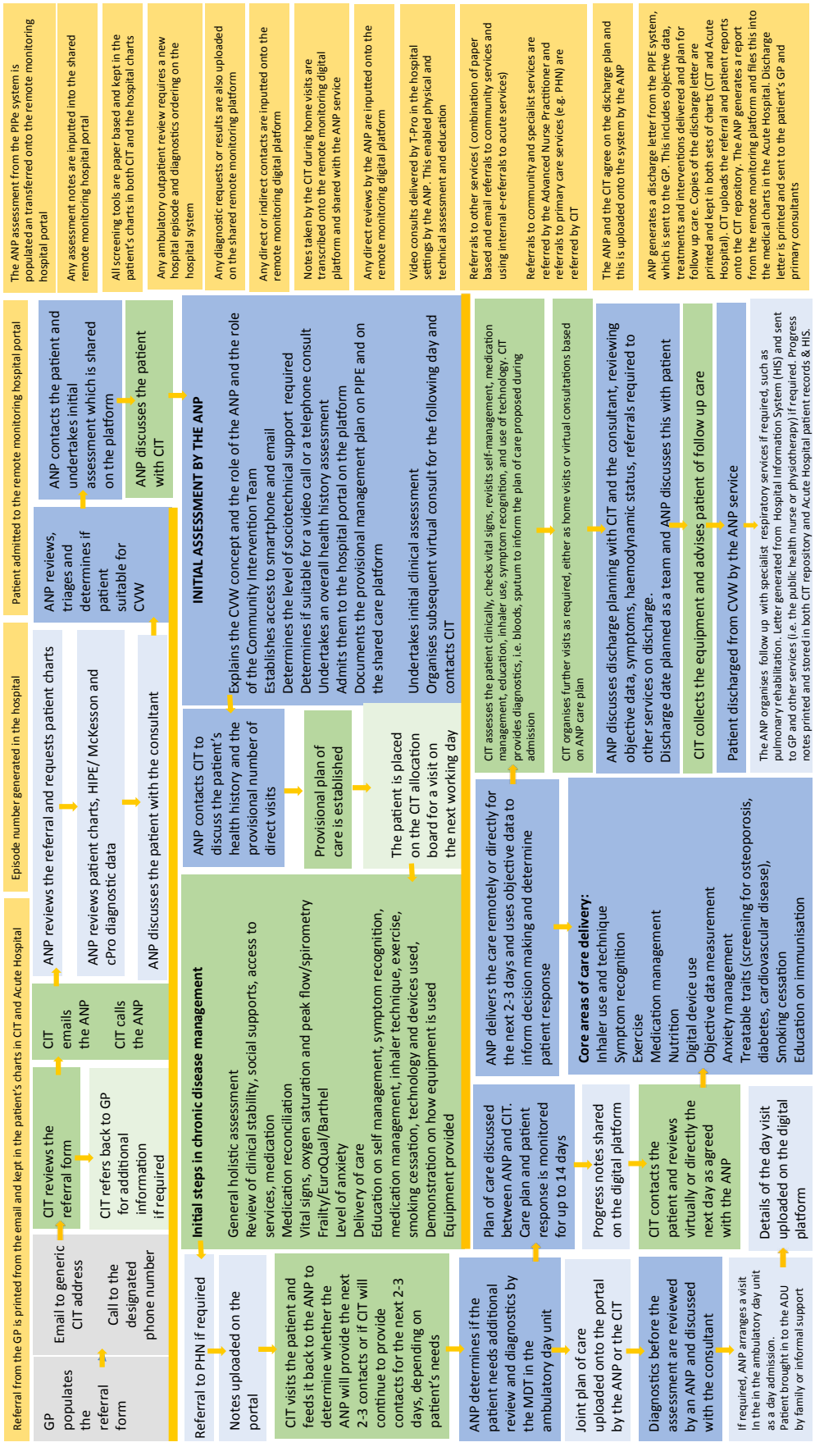
Paper Based	Administrative Duplication
Referral form paper based & accessible on the digital remote monitoring platform. Paper-based screening tools. Paper-based patient records.	Electronic assessment completed on a separate system and uploaded into the remote platform. Increase in administration to create hospital episodes and order diagnostics on different systems. Referral process to services separate Community/Hospital (mix of paper and electronic referrals). Communication (discharge letters) generated on a separate system and uploaded to the remote monitoring digital platform.
Integration	**Unstructured data**
Separate modes of information sharing (email, remote monitoring platform, hospital information system). Separate systems to populate information (CIT and Acute Hospital paper-based file, Hospital Information System, Remote Monitoring Community/Hospital Portal). Separate systems to gather historical and current information on patients (for example episodes of care, outpatient letters, diagnostics, blood chemistry).	Unstructured data/free text recording of patient care (challenges in measuring impact of care and measuring cost efficiency). Referral process to services separate Community/Hospital (mix of electronic and paper based).

Figure. 9 Key Areas for of information movement in the Community Virtual Ward



There are several steps that can assist in addressing these challenges as part of wider testing for draft policy. This includes utilisation of existing digital solutions, for example Healthlink (messaging and referral system) and the Patient Administration System (PAS), that can assist in streamlining information coupled with structuring data to measure efficiency, effectiveness, and impact (for example core interventions, diagnostics, contact remote versus face-to-face). Several solutions have been developed and deployed as part of COVID-19 response (remote monitoring platforms with capability to integrate with existing systems, scheduling systems and web-based platforms that can integrate with remote monitoring systems to facilitate information movement, access to a suite of digital screening tools, access to digital templates for referrals and discharge letters, and streamlined referral pathways). These solutions have the capability to integrate with hospital and community systems to support the testing of a CVW draft policy. However, to support longer term reform and ensure sustainability the two key enablers are the i) ***Individual Health Identifier*** (IHI) and ii) ***Shared Care Record.*** The IHI is a unique number that will be used to safely identify an individual and their health information when using a health service. This assists in tracking touchpoints of care in the system and transfer of information across acute and community services (public/private and cross-border). The Shared Care Record has the capability to collect data from the health and social care systems used by all the care providers, including GPs, acute hospitals, and community services.

Figure.10 Process Map of Patient Journey & Information Steps Community Virtual Ward Model



5.0 | Case Studies

In this section, examples of case studies are presented to support the mapping process and demonstrate the patient journey from admission to discharge. These are generic case studies that represent the journey of patients admitted to the CVW and names are not representative of any patient admitted to the CVW during testing.

Maeve is a 70yr old lady with stage 2, grade B COPD. While attending a routine respiratory out- patient appointment she is diagnosed with an acute exacerbation of her COPD. She has been hospitalised previously and has attended her GP on at least 4 occasions in the previous year. The decision is made to refer her to the CVW for admission and treatment instead of admitting to hospital.

Maeve is reviewed in the respiratory out -patient clinic and on history and physical exam is found to have an exacerbation of her COPD. The patient is risk stratified and a decision is made to treat from home and referral is made to the CVW. Patient agrees for admission to the CVW.

Day 1 Acute Hospital Care

Following review in OPD, the patient is referred and accepted to the CVW. Respiratory registrar in OPD prescribes oral antibiotics and steroids for the patient on discharge. ANP in CVW sends prescription to patient's pharmacy using Health mail. CIT contacted re patients 'admission.

→ Medication delivered to patient at home

Day 2-3

CIT nurses review patient at home and liaise with ANP Patient experiences increased SOB and increased work of breathing. CIT contact ANP re deterioration in patients condition. ANP performs telephone review and determines patient requires physical review in hospital.

→ Escalation →

ANP reviews patient in Ambulatory Day ward. Physical assessment, bloods and CXR performed

Day 4-6

Following in-hospital review, nebuliser is organised to aid sputum expectoration and same is delivered by CIT nurses. Patient is noted to have > than 7kg weight loss in previous months and dietician referral is sent.

Day 6-12

Treatment and education by cANP and CIT nurses continues. Patient has noticeable hoarseness of voice and coupled with weight loss prompts cANP to discuss patient with respiratory consultant. Overall condition is improving.

→ Post MDM discussion patient is referred for urgent ENT review

Day 13

Following telephone review of patient and discussion at MDM with respiratory consultant patient's condition is improved and she is discharged from the CVW. ENT organised for the following week. Referrals made to community dietician and chronic disease management team.

Thomas is a 50-year-old gentleman admitted following a life-threatening asthma attack. Thomas reports having symptoms of asthma exacerbation two weeks prior to this event but refused admission to hospital. On discharge Thomas is referred to the CVW team and accepted.

Thomas is admitted to hospital following collapse and respiratory arrest at home. He is intubated in the ED department and transfered to ICU. Thomas has no previous hospitalisations with asthma but given the severity of attack is deemed high risk for further exacerbations.

Day 1-3 Acute Hospital Care

Thomas is intubated on admission to ED and spends 24hrs in ICU before transfer to acute respiratory ward. He is treated with IV steroids, IV antibiotics and nebulisers. He has negative COVID swab. He is reviewed by his consultant and is discharged for follow up with asthma.

Day 4 Acute Hospital Care

Patient is referred to the CVW by asthma consultant for monitoring and education of condition, review of inhaled medication and proper administration technique. Patient is very anxious on discharge. Referral reviewed by CVW consultant and ANP and patient to accepted to CVW.

Day 1 CVW

Patient is contacted by ANP and consent for enrolment to CVW is agreed. ANP contacts CIT and monitoring equipment is brought to patients home. ANP completes full admission assessment by telephone with patient and identifies key interventions required for patient during his admission.

Day 2-6

Patient begins monitoring vital signs and spirometry. ANP conducts detailed telephone review with patient and disease management and inhaler medication use explained.

MDM discussion with Consultant to arrange follow up care

Day 7

ANP conducts telephone review of patient's condition. Data is reviewed and plan for follow up blood tests and formal spirometry organised. Patient is for follow up with GP and specialist asthma consultant from CVW.

Joan is a 57-year-old lady with a history of stage 3 COPD and obstructive sleep apnoea, requiring home non-invasive ventilation. She has required multiple courses of antibiotics throughout the last year and the respiratory team have been unable to wean her steroid dose below 10 mgs for the previous 3 years. She has been referred for admission to the CVW for tele-monitoring and weaning of steroids by 1mg weekly.

Joan is referred to the CVW from the respiratory out-patient service. ANP reviews patient's charts and following discussion with the Consultant admits patients for education and steroid reduction.

Day 1-6

Patient is assessed by the ANP for the CVW and following MDM discussion with Consultant decision made to keep patient on maintenance dose of steroid 10mgs for 1 week and commence Tele-monitoring. CIT contacted and informed of plan of care.

→ ANP remotely monitors

Day 7-14

ANP remotely monitors progress and on day 7 begins to reduce patient's oral steroid dose in increments. Reassurance and support around need for reduction given to patient.

Day 14-20

Patient's steroid reduced down to 7mgs at midway point in treatment. Patient received inhaler education and advice on the correct use of home oxygen. Anxiety continues over weaning of steroids reassurance given by ANP. CIT nurses visit patient and reinforce education.

→ Referral made to Respiratory Physio re: oxygen review

Day 20-23

Patient remains stable and steroid weaning continues. Patients has been weaned down to 5mgs of oral steroid. Patient reports noticeable improvement in SOB on exertion with correct use of her oxygen.

Day 24 – Discharge from CVW

Patient is for discharge from CVW. Currently on 5mgs of steroid and she will be followed up in the respiratory consultant led clinic to continue to wean steroids as tolerated. She has also been referred to the Endocrine team and has an appointment one week post discharge from the CVW.

6.0 | Model Costs

In this chapter the model costs and cost efficiencies will be presented. The Safe Staffing and Skill Mix Framework (DOH 2018b) was the methodology applied to assist in determining staff resource and cost staffing resources (Table 7). These costs are based on the POC in terms of acuity and dependency levels, level of direct and indirect care, the referral process, triage process, care co-ordination, interventions, discharge planning and referral onwards. On review of the CVW co-ordinator role inclusive of duties a CNM2 grade would be required supported by a CNM1.

Table 7 Community Virtual Ward Resource Cost

Role	Role	Salary	PRSI	WTE	Total Cost
		Mid-Point of Salary	Include PRSI etc	WTE	Cost
Enhanced Nurse scale	ENP	€42,772.00	€52,182	5	€260,909.20
Clinical Nurse manger 1	CNM	€50,191.00	€11,042	2.5	€27,605.05
Advanced Nurse Practitioner	ANP	€65,862.00	€80,352	2	€160,703.28
Clinical Nurse manger 2	CNM	€54,920.00	€67,002	1	€67,002.40
Admin support	AS	€31,826.00	€38,828	1	€38,827.72
Health care assistant	HCA	€33,169.00	€40,466	2.5	€101,165.45
				Total Cost	**€628,608.05**

The remote technology platform is inclusive of devices and this is the cost for a testing phase in three sites (Table 8).

Table 8 Cost of the Remote Monitoring Platform Inclusive of Devices

Remote monitoring platform	Per Patient	Site
Description	Unit Cost in Euros	Total Cost
Set up fees	19	€37,620
Monitoring Cost	12	€5,940
Total Cost		**€43,750**

Cost of CVW and Acute Hospital Comparator

The figures presented are based on the total cost of the CVW inclusive of the remote monitoring platform and an average length of stay of 11 days for approximately 1,980 patients over three sites for a duration of 12-months. The cost of an acute hospital admission per day is estimated as €820 in comparison to a CVW admission of **€88** per day. The total cost per patient for an admission to the CVW based on 11-days LOS is **€969** compared to **€9,020** in an acute hospital.

The total cost of care over a 12-month period across three CVW sites is **€1,929,574**. This is based on a 20 bed CVW catering for 660 patients in each of the three sites over this timeframe. The estimated total number of patients accessing the CVW in the 12-month period is 1,980. The cost of care per site is estimated as **€639,540.** This has been compared to the cost of an acute hospital admission based on 20-beds for a total of 660 patients with an estimated cost of **€5,953,200** (Table 9). This equates to a total accumulative cost of **€17,859,600** based on 1,980 patients over the 12-month timeframe. It is estimated a CVW across three sites has the potential to result in a **total cost saving** in care delivery of **€15,930,026.**

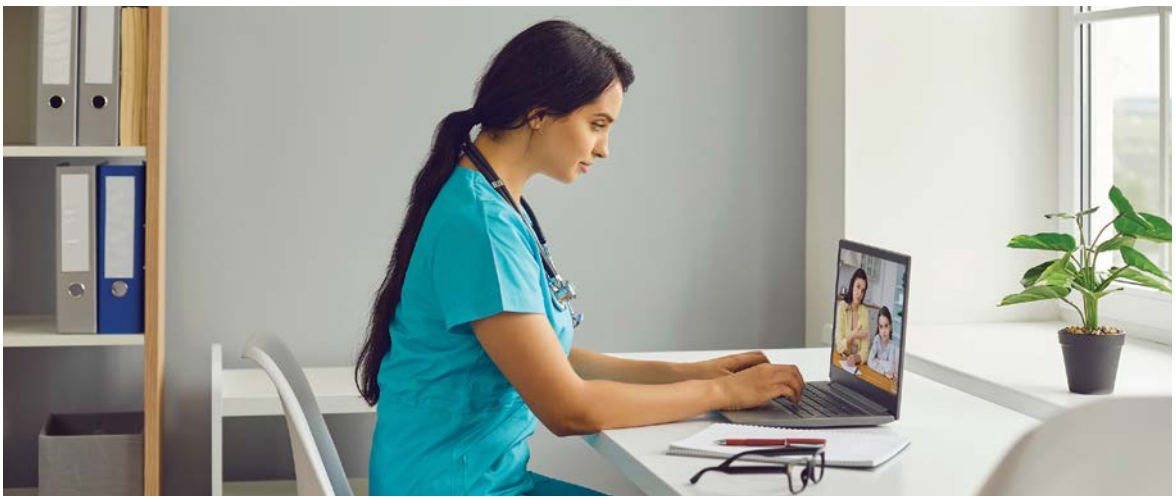
Table 9 Estimated Costs over a 12-month Period CVW and Acute Hospital Comparator

	Per Day	Cost of Admission	Total Cost
CVW	€88	€969	€639,540
Acute Hospital	€820	€9,020	€5,953,200

7.0 | Community Virtual Ward Opportunities

The testing of the POC has shown the capability of a CVW and offers several opportunities to support the delivery of Sláintecare and the role of the EN. This includes;

1	Extending skills in areas of practice that are community focused to support service redesign and healthcare reform to meet the needs of the population.
2	Developing a capability framework for the Enhanced Nurse building on the core areas of care identified as part of testing the POC. This will maximise on a blend of specialist and generalist practice to build on the domains of competence under clinical, social, behavioural, functional, nutritional, technical and educational.
3	Technology enabled models of care to support service re-design and integration maximising on flexibility of roles using remote monitoring, remote monitoring devices and real-time sharing of information electronically. This was essential to integrate care delivery and assisted in focusing the shift in acute care to the community.
4	Development of a hybrid approach to care with a blend of expert specialist and specialist generalist that is a broad-based approach to care for patients living with longterm conditions and complex healthcare needs.
5	Reduce the demand for inpatient and emergency care as well as equity in terms of resources across acute and community to support the delivery of a CVW.
6	Reduce duplication of care due to acute and community engagement as a shared approach.
7	Ensure that the care pathway is a continuum from acute and community so that the services reflect the needs of the patients accessing the CVW and on discharge.



Community Virtual Ward Strengths

As well as opportunities, there are several strengths and limitations in the delivery of a CVW model. The strengths include;

1	It is an integrated model providing enhanced care that is inclusive of acute and community care.
2	It provides an environment to deliver case-management approaches to care.
3	Patients access care at home and have choice about the type of interventions delivered including engagement with technology.
4	It is more cost efficient and cost effective to deliver this type of care in the home versus the acute hospital.
5	Provides a model of care to deliver effective remote care.
6	It is a collaborative, shared care approach capitalising on the unique skills developed in acute and community areas to ensure the patient and family is maximising on the knowledge and expertise across the healthcare continuum.
7	It provides an environment to support nurses (ENs) to work to the top of their licence.

Community Virtual Ward Limitations

As well as strengths there are several limitations that will be reviewed and evaluated as part of wider testing with recommendations for proposed solutions. The limitations include;

1	Multiple information sources accessed by acute hospital and community. This includes diagnostics, referrals to other services, discharge information.
2	Use of unstructured data.
3	Paper based systems inclusive of screening tools.
4	Socio-technical support and difficulties for patients using and accessing smart technology.
5	Access to diagnostics in the community.

Solutions for the above will be considered as part of wider piloting and recommendations included in the evaluation of the CVW.

8.0 | Conclusion

The purpose of testing a POC CVW was to determine design and functionality of this model of care to support the EN role and integrate nursing services. This will facilitate a sustainable shift of care from the acute setting to community through reorganisation of nursing resources.

The outcomes identified in this report have shown the capability and impact of a CVW on the following;

i. Improved patient outcomes, management of sub-acute care.
ii. Coordination of services provided to CVW patients, which extended beyond COPD management towards working with other services to provide early intervention for signs of frailty, anxiety/depression management, weight loss and functional decline.
iii. A clear clinical governance structure in place.
iv. Increasing level of integration between acute and community settings, including establishment of scalable and replicable pathways which can form a basis for other forms of acute/community cooperation.
v. Staff mix to reflect the needs of local high-risk patients.
vi. Clear out of hours arrangements.
vii. Alert system in place to ensure escalation pathways were implemented.
viii. Regular ward rounds including acute and community nursing staff.
ix. A single point of contact for patients and families.
x. Economic impact, including cost effectiveness and log-term cost efficiencies of this model of care.
xi. Providing safe patient care that allows timely access to interventions and services, follows best practices, evidence-based guideline management, and incorporates patients' preferences and treatment priorities.

The success of the proof of concept CVW is reflected in both the clinical outcomes and in the feedback collected from clinicians, nurses, GPs, and patients themselves. This has demonstrated that CVW has the capacity to support Sláintecare and development of regional integrated care models for a scalable and sustainable shift in care.

The CVW provides a generic model that can be scaled to provide acute care in areas such as chronic disease (for example respiratory, heart failure, diabetes) and older persons care (inclusive of residential care settings). This can be delivered under real world conditions in the community by applying the principles of the model to reach a greater proportion of the eligible population, whilst retaining effectiveness and efficiency. Thereby, tailoring the use of digital health care, remote monitoring, the governance, and level of integration required depending on regional and local healthcare needs.

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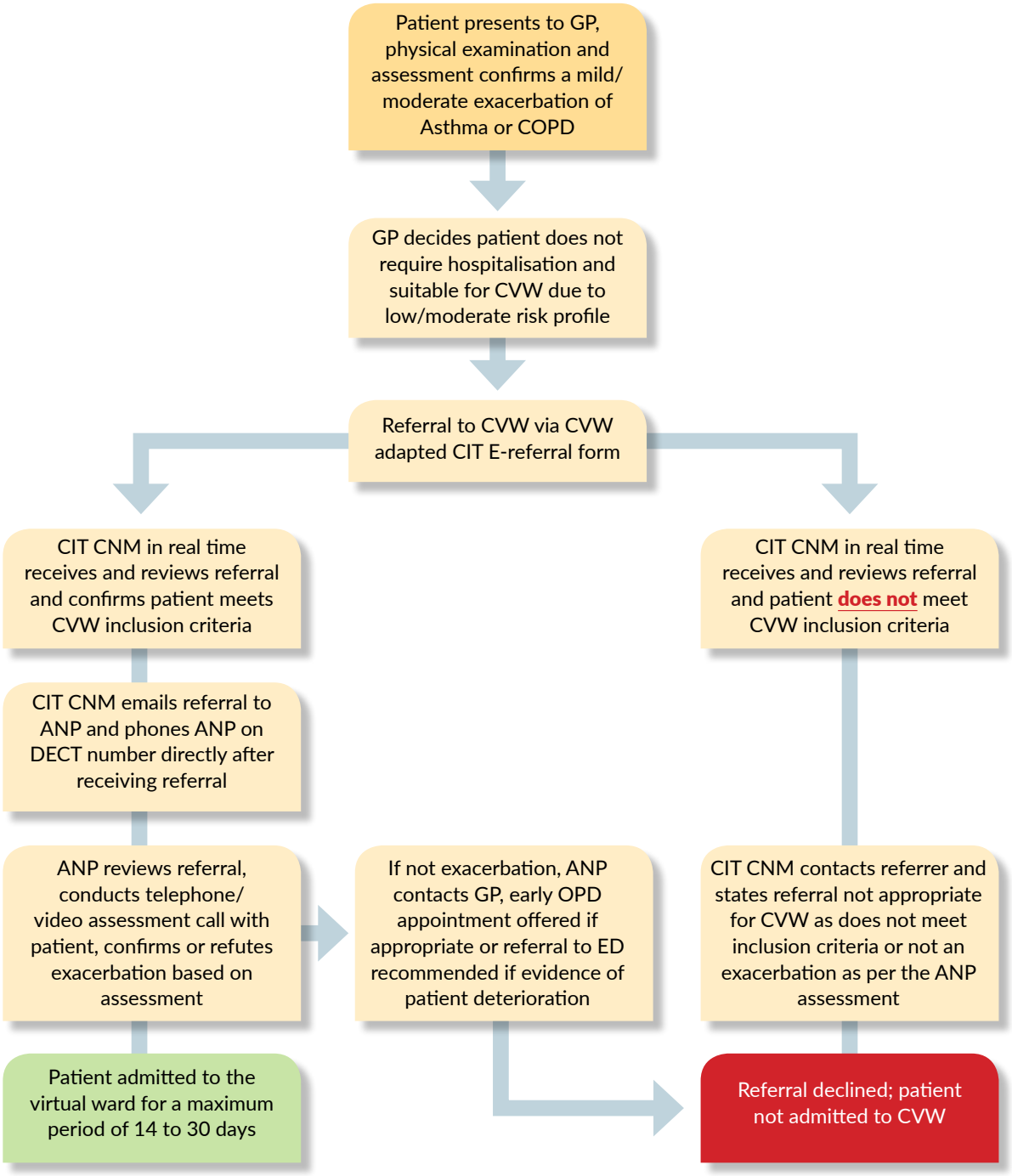
Appendix 1

Community Virtual Ward Inclusion and Exclusion Criteria & Pathway

Community Virtual Ward Inclusion and Exclusion Criteria & Pathway

Inclusion Criteria	Red Flags- Hospitalisation Criteria
✓ Over 16 years of age. ✓ Primary resident of Beaumont catchment area. ✓ No active addiction or members of household with active addiction ✓ Known to one of the Beaumont Respiratory Consultants ✓ Spirometry diagnosed Asthma or COPD ✓ Baseline spirometry accessible and available ✓ Physical examination completed by referring GP ✓ Mild/ moderate exacerbation or ongoing decline from baseline: criteria for this to be confirmed ✓ Optimal home care supports in place, to support with activities of daily living. ✓ Does not require an intensive programme of case-management. ✓ Nominated GP practice included in pilot ✓ Tested negative for COVID-19 and no clinical suspension of same	HR >120 pm, RR>30 pm, SpO2 <90%, Worsening resting dyspnoea Unable to complete sentence High respiratory rate Decreased oxygen saturations Acute respiratory failure Stridor Onset of new physical signs (cyanosis, peripheral oedema). Failure of exacerbation to respond to initial medical management. Evidence of de-compensation of a long-term condition (e.g. heart failure, arrhythmia) with acute symptoms that requires acute hospital direct interventions and monitoring due to the presence of serious co-morbidity (heart failure, new occurring arrhythmias, etc.)

Community Virtual Ward Pathway



Appendix 2

CVW Escalation Pathways for Out of Hours

Community Virtual Ward Escalation Pathway for Out of Hours CNMs

Escalation Pathway

Telephone call from CIT
CIT available 8am-8pm on 01 xxxxxxxx

1. Log in to hospital remote monitoring portal
2. Review documentation from earlier in the day from cANP and CIT
3. Any abnormal parameters or patient concerns, as below

Abnormal:
Resting Heart Rate >100bpm
OR
Resting O2 Saturations <92%

1. Escalate to Medical Register on call
2. Document episode on hospital remote monitoring portal

Red Flags – Hospitalisation Criteria

1. HR>120pm, RR>3pm, SpO2<90%
2. Worsening resting dyspnoea
3. Unable to complete sentence
4. Acute respiratory failure
5. Stridor
6. Onset of new physical signs (cyanosis, peripheral oedema)
7. Staff concerned patient not coping
8. Evidence of decompensation of a long-term condition with acute symptoms (e.g. heart failure, arrhytmia)

Telephone Call from Patient

1. Log on to remote monitoring hospital portal
2. Review documentation from earlier in the day from cANP and CIT

Patient seeking IT support

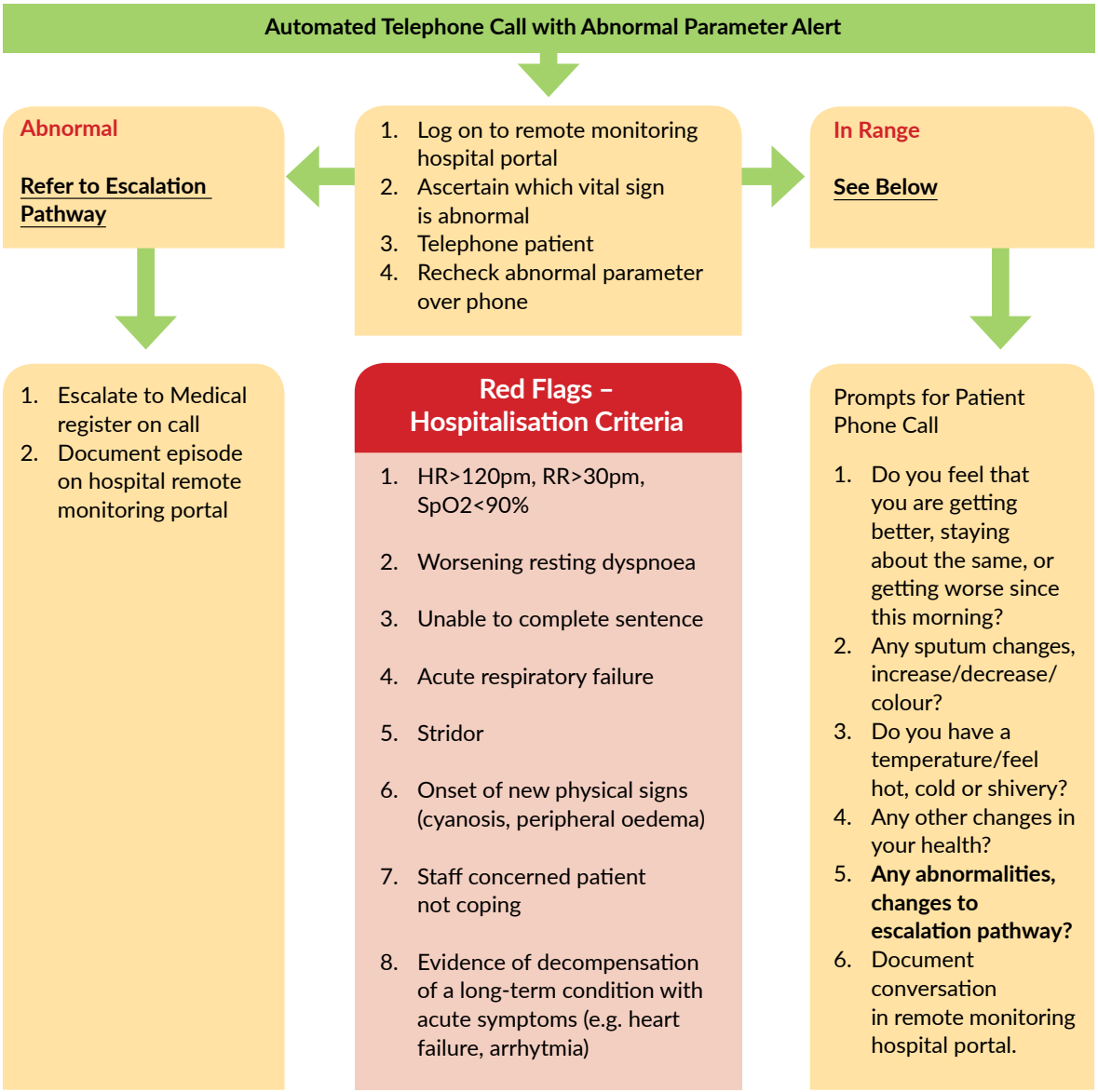
Prompts for Patient Phone Call

1. Provide patient remote monitoring technical support patient IT support number or email address:
2. HCP support via email, also via above contact number

Patient seeking nursing advice

Prompts for Patient Phone Call

1. Do you feel that you are getting better, staying about the same, or getting worse since this morning?
2. Any sputum changes, increase/decrease/colour?
3. Do you have a temperature/feel hot, cold or shivery?
4. Any other changes in your health?
5. **Any abnormalities, changes to escalation pathway?**
6. Document conversation in remote monitoring technical support teams


Automated Telephone Call with Abnormal Parameter Alert
Abnormal
Refer to Escalation Pathway
1. Log on to remote monitoring hospital portal
2. Ascertain which vital sign is abnormal
3. Telephone patient
4. Recheck abnormal parameter over phone
In Range
See Below
1. Escalate to Medical register on call
2. Document episode on hospital remote monitoring portal
Red Flags – Hospitalisation Criteria
1. HR>120pm, RR>30pm, SpO2<90%
2. Worsening resting dyspnoea
3. Unable to complete sentence
4. Acute respiratory failure
5. Stridor
6. Onset of new physical signs (cyanosis, peripheral oedema)
7. Staff concerned patient not coping
8. Evidence of decompensation of a long-term condition with acute symptoms (e.g. heart failure, arrhytmia)
Prompts for Patient Phone Call
1. Do you feel that you are getting better, staying about the same, or getting worse since this morning?
2. Any sputum changes, increase/decrease/ colour?
3. Do you have a temperature/feel hot, cold or shivery?
4. Any other changes in your health?
5. Any abnormalities, changes to escalation pathway?
6. Document conversation in remote monitoring hospital portal.

Appendix 3

Screening Tools

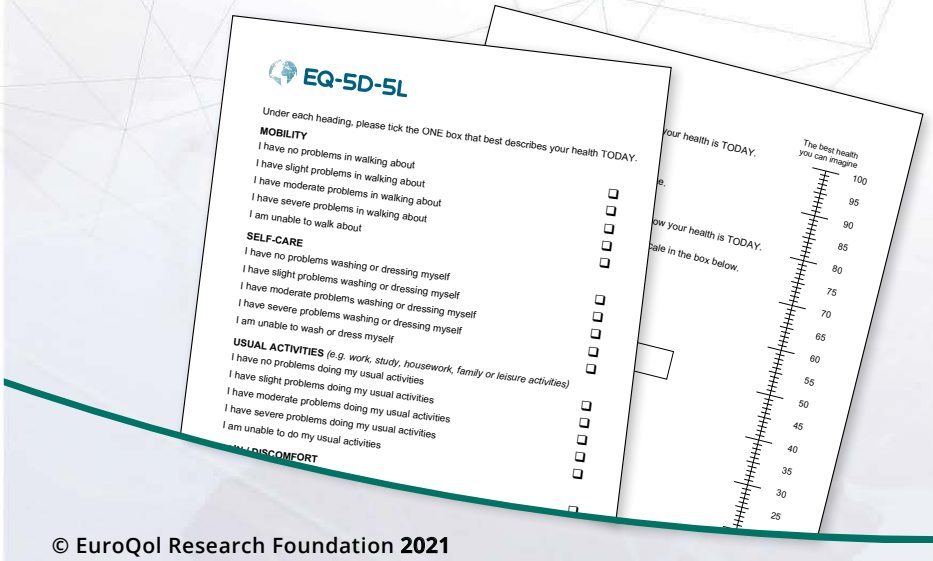
MODIFIED MRC DYSPNEA SCALE[a]		
PLEASE TICK IN THE BOX THAT APPLIES TO YOU | ONE BOX ONLY | Grades 0 - 4		
mMRC Grade 0.	I only get breathless with strenuous exercise.	☐
nMRC Grade 1.	I get short of breath when hurrying on the level or walking up a slight hill.	☐
mMRC Grade 2.	I walk slower than people of the same age on the level because of breathlessness, or I have to stop for breath when walking on my own pace on the level.	☐
mMRC Grade 3.	I stop for breath after walking about 100 meters or after a few minutes on the level.	☐
mMRC Grade 4.	I am too breathless to leave the house or I am breathless when dressing or undressing.	☐

[a] Fletcher CM. BMJ 1960; 2: 1662.

EQ-5D

EQ-5D-5L User Guide

Basic information on how to use the EQ-5D-5L instrument



Version 3.0

Updated
September 2019

CHANGES INCLUDED
in this update of the EQ-5D-5L User Guide

Updates have been made to nearly all sections of the User Guide, including: a significantly revised section on how to present results; inclusion of a list of available standard value sets and ongoing EQ-5D-5L valuation studies; expanded descriptions of available modes of administration and translations; inclusion of information boxes (e.g. about publications comparing the EQ-5D-3L and EQ-5D-5L; example text for study protocols). Following the launch of the new EuroQol website – which contains regularly updated, detailed information about the EQ-5D – this update of the User Guide also refers the user to relevant webpages, using hyperlinks, for the latest information on a given topic.

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How to obtain the EQ-5D: To register your interest in using the EQ-5D for your study/trial/project, please complete the registration form on the **EuroQol website**. The EuroQol office will then contact you by e-mail and inform you about the terms and conditions that apply to your use of the EQ-5D, including licensing fees (if applicable).

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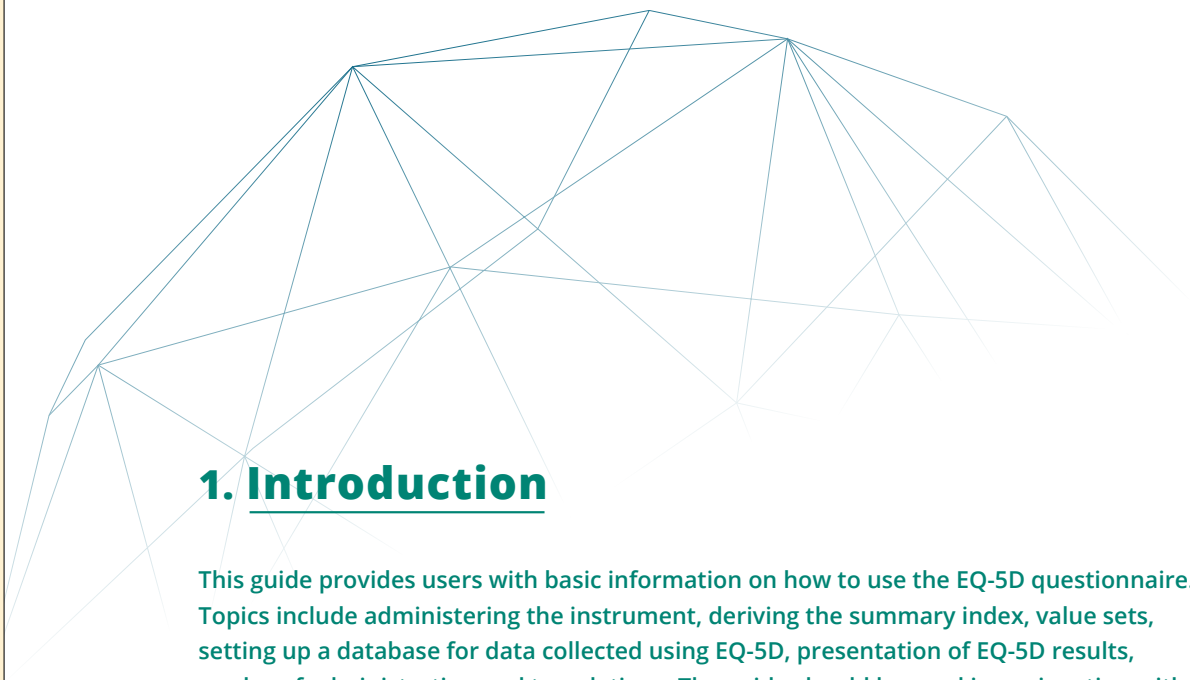


1. Introduction

This guide provides users with basic information on how to use the EQ-5D questionnaire. Topics include administering the instrument, deriving the summary index, value sets, setting up a database for data collected using EQ-5D, presentation of EQ-5D results, modes of administration and translations. The guide should be used in conjunction with the EuroQol website, which contains regularly updated, detailed information about the EQ-5D (see below). Where appropriate, weblinks to relevant resources on the EuroQol website are provided in this guide. For further information or assistance regarding the use of the EQ-5D, you can also contact the EuroQol office directly.

1.1 / EUROQOL

EuroQol* consists of a Research Foundation and a Group Association. The EuroQol Research Foundation is a not-for-profit organisation that supports, initiates and performs scientific research and development of instruments that describe and value health. The Foundation is responsible for the development of the EQ-5D, a preference-based measure of health status that is widely used around the world in clinical trials, population studies and real-world clinical settings. The EQ-5D is recommended by several health technology assessment bodies internationally as a key component of cost-utility analysis.

The EuroQol Group Association consists of a large global network of experts, from a wide range of academic disciplines and countries, who are committed to ongoing research on the EQ-5D family of instruments.

The scientific expertise behind EuroQol is the EuroQol Group Association, an international network of multidisciplinary researchers dedicated to the measurement of health status. When established in 1987, the EuroQol Group Association originally consisted of researchers from Europe. Today, it is a global network of more than 90 members from Africa, Asia, Europe, North America, Oceania and South America.

EuroQol can be justifiably proud of its collective scientific achievements over the last 30 years. Research areas include: the investigation and application of different valuation methodologies to obtain health state values for use in cost-effectiveness analysis, development of value sets for health states, EQ-5D use in clinical studies and in population surveys, experimentation with the EQ-5D descriptive

* The organisational structure is provided on the EuroQol website.

system, computerised applications, interpretation of EQ-5D responses, the role of EQ-5D in measuring social inequalities in self-reported health, and the measurement and valuation of health in younger populations. The EuroQol Group Association has been holding annual scientific meetings since its inception in 1987.

EuroQol is a registered not-for-profit organisation that invests all income into EQ-5D research, education and user support.

The EuroQol Research Foundation is a registered not-for-profit organisation in the Netherlands and the single organisation that manages the distribution and licensing of the EQ-5D family of instruments worldwide. The EuroQol Group invests all income into EQ-5D research, education and user support.

The **EuroQol website** provides detailed information and updates on the EQ-5D, guidance for users, a list of available language versions and value sets by country/region, key EQ-5D references, frequently asked questions regarding the use of EQ-5D, EQ-5D registration process and forms, information about the EuroQol Group organisation and contact details.

1.2 / EQ-5D®

EQ-5D is a standardised measure of health status developed by the EuroQol Group to provide a simple, generic measure of health for clinical and economic appraisal.[1]

The EQ-5D family of instruments has been developed to describe and value health across a wide range of disease areas. They are also frequently used in research into health in the general population. There are three versions of the instrument: **EQ-5D-5L**, **EQ-5D-3L** and **EQ-5D-Y**. For over 25 years, they have been widely used in clinical trials, population studies and in real-world clinical settings. The EQ-5D is used worldwide and has been translated into most major languages through a closely monitored translation process.

Each EQ-5D instrument comprises a short **descriptive system** questionnaire and a **visual analogue scale** (**EQ VAS**) that are cognitively undemanding, taking only a few minutes to complete. The questionnaire provides a simple descriptive profile of a respondent's health state. The EQ VAS provides an alternative way to elicit an individual's rating of their own overall current health. When the descriptive system profile is linked to a '**value set**', a single summary index value for health status is derived that can be used in economic evaluations of healthcare interventions. A value set provides values (weights) for each health state description according to the preferences of the general population of a country/region. Value sets for the EQ-5D-5L and 3L versions are available in a large and growing number of countries (see **Section 4**).

Designed for self-completion by respondents and available in both paper and digital versions, the EQ-5D is ideally suited for use in online or postal surveys, in clinics and in interviews (face-to-face or telephone). Proxy versions are also available for populations in which self-completion is not possible (see **Section 7.2**). Instructions to respondents are included in the questionnaire.

Note: The EQ-5D is not an abbreviation and is the correct term to use in print or verbally.

1.3/EQ-5D-3L

The EQ-5D three-level (3L) version was introduced in 1990. The standard paper-based, self-complete version consists of a title page, the descriptive system (on page 2), and the EQ VAS (on page 3).

- The EQ-5D-3L descriptive system comprises the following five dimensions, each describing a different aspect of health: **MOBILITY**, **SELF-CARE**, **USUAL ACTIVITIES**, **PAIN / DISCOMFORT** and **ANXIETY / DEPRESSION**. Each dimension has three response levels of severity: no problems, some problems, extreme problems. The respondent is asked to indicate his/her health state by checking the box next to the most appropriate response level of each of the five dimensions.
- The EQ VAS records the respondent's self-rated health on a vertical VAS where the endpoints are labelled 'The best health you can imagine' and 'The worst health you can imagine'. This information can be used as a quantitative measure of health outcome as judged by the individual respondents.

The EQ-5D-3L is one of the most widely used instruments worldwide for measuring health status and the self-complete language version has been translated into over 180 languages. The EQ-5D-3L has been proven to be valid, reliable and responsive in numerous conditions and populations.[2]

1.4/EQ-5D-5L

In 2005, a research programme was implemented to investigate methods to further improve the EQ-5D-3L's sensitivity.[3] After much deliberation, it was decided that there should be no change in the number of dimensions for a new version of EQ-5D. However, previously published studies by EuroQol Group members showed that experimental five-level (5L) versions of EQ-5D could significantly increase reliability and sensitivity (discriminatory power) while maintaining feasibility and potentially reducing ceiling effects.[4–7] The Group therefore decided that the new version of the EQ-5D should include five levels of severity in each of the existing five EQ-5D dimensions and that it would be called the EQ-5D-5L (Figure 1). In addition, the most severe label for the mobility dimension was changed from 'I am confined to bed' to 'I am unable to walk about', enhancing its applicability and increasing the sensitivity of the mobility dimension. The EQ VAS layout, method for marking a response and instructions were simplified in the EQ-5D-5L, compared with the original VAS used in the EQ-5D-3L, making the task easier to complete and easier to score.* The existing EQ-5D was renamed the EQ-5D-3L. The research underpinning the development and preliminary testing of the EQ-5D-5L is summarised on the **EuroQol website**.[8]

As with the 3L version, the standard paper-based, self-complete version of the EQ-5D-5L still consists of three pages – the title page, the EQ-5D-5L descriptive system (on page 2) and the EQ VAS (page 3).

The EQ-5D-5L descriptive system comprises the same five dimensions as the EQ-5D-3L (MOBILITY, SELF-CARE, USUAL ACTIVITIES, PAIN / DISCOMFORT and ANXIETY / DEPRESSION), but each dimension now has five response levels: no problems, slight problems, moderate problems, severe problems, unable to/extreme problems. The respondent is asked to indicate his/her health state by checking the box next to the most appropriate response level for each

6

* As of 2018, the EQ VAS in all versions of the EQ-5D-3L has been updated to match the VAS format used in the EQ-5D-5L.

of the five dimensions. Responses are coded as single-digit numbers expressing the severity level selected in each dimension. For instance, 'slight problems' (e.g. 'I have slight problems in walking about') is always coded as '2'. The digits for the five dimensions can be combined in a 5-digit code that describes the respondent's health state; for instance, 21111 means slight problems in the mobility dimension and no problems in any of the other dimensions (see Section 2 for further information on how to score the descriptive system).

The EQ VAS records the respondent's overall current health on a vertical visual analogue scale, where the endpoints are labelled 'The best health you can imagine' and 'The worst health you can imagine'. The EQ VAS provides a quantitative measure of the patient's perception of their overall health.

SEVERITY LEVELS for dimensions in the descriptive system

The numbers representing the five severity levels of a dimension are labels used in the numerical description of a health state (see Section 2.1). They have no arithmetic properties. For instance, on the basis of just the numbers one cannot assume that a state 21111 is better 13111. Therefore, these numbers should not be used to derive a summary score. To derive the summary index score, an appropriate 'value set' is required (see Section 4).

PUBLICATIONS COMPARING the EQ-5D-3L and EQ-5D-5L

The EuroQol website includes a continuously updated section on publications comparing the EQ-5D-3L and EQ-5D-5L. The section is subdivided into publications comparing the descriptive systems, value sets, implications for cost effectiveness analysis, commentaries, editorials and institutional guidance documents. Please note that comparative performance across patient groups is driven by differences in the descriptive systems **and** the associated value sets. Since countries use different value sets, the differences between EQ-5D-3L and EQ-5D-5L can be country/region-specific.

A good starting point for an overview of the differences in measurement properties between EQ-5D-3L and EQ-5D-5L is:

- A systematic review of studies comparing the two instruments by Buchholz and colleagues (2018).[9] The review concluded by supporting the use of the EQ-5D-3L and EQ-5D-5L in a broad range of patients, populations and countries/regions, while noting that the EQ-5D-5L showed better or at least similar measurement properties to the EQ-5D-3L.
- A head-to-head comparison of descriptive systems and value sets across seven countries (Canada, China, England/UK, Japan, Netherlands, South Korea and Spain) by Janssen and colleagues (2018).[10] The study found that the EQ-5D-5L is superior to the EQ-5D-3L with respect to various measurement properties, enabling improvements in sensitivity and precision in health status measurement. It recommends the EQ-5D-5L for use across applications, including economic evaluation, clinical studies, quality of care and in public health studies.

Figure 1 / UK (English) EQ-5D-5L Paper Self-Complete (sample version)

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

SELF-CARE

I have no problems washing or dressing myself ❑
I have slight problems washing or dressing myself ❑
I have moderate problems washing or dressing myself ❑
I have severe problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

USUAL ACTIVITIES (*e.g. work, study, housework, family or leisure activities*)

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

PAIN / DISCOMFORT

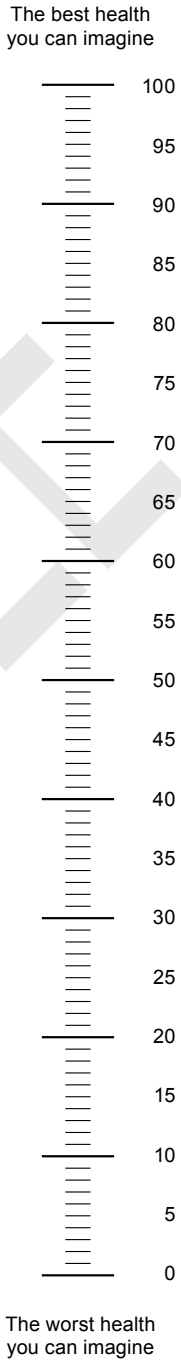
I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



2. Scoring the EQ-5D-5L descriptive system

This example shows how a health state is described using the EQ-5D-5L descriptive system:

Under each heading, please tick the ONE box that best describes your health TODAY.

		Levels of perceived problems are coded as follows:
MOBILITY		
I have no problems in walking about	☑	☑
I have slight problems in walking about	☐	☐
I have moderate problems in walking about	☐	☐
I have severe problems in walking about	☐	☐
I am unable to walk about	☐	☐ Level 1 is coded as a '1'
SELF-CARE		
I have no problems washing or dressing myself	☐	☐
I have slight problems washing or dressing myself	☑	☑
I have moderate problems washing or dressing myself	☐	☐
I have severe problems washing or dressing myself	☐	☐
I am unable to wash or dress myself	☐	☐ Level 2 is coded as a '2'
USUAL ACTIVITIES (*e.g. work, study, housework, family or leisure activities*)		
I have no problems doing my usual activities	☐	☐
I have slight problems doing my usual activities	☐	☐
I have moderate problems doing my usual activities	☑	☑
I have severe problems doing my usual activities	☐	☐
I am unable to do my usual activities	☐	☐ Level 3 is coded as a '3'
PAIN / DISCOMFORT		
I have no pain or discomfort	☐	☐
I have slight pain or discomfort	☐	☐
I have moderate pain or discomfort	☐	☐
I have severe pain or discomfort	☑	☑
I have extreme pain or discomfort	☐	☐ Level 4 is coded as a '4'
ANXIETY / DEPRESSION		
I am not anxious or depressed	☐	☐
I am slightly anxious or depressed	☐	☐
I am moderately anxious or depressed	☐	☐
I am severely anxious or depressed	☐	☐
I am extremely anxious or depressed	☑	☑ Level 5 is coded as a '5'

This example identifies the health state '12345'.

Notes:

- There should be only ONE response for each dimension
- Missing values are preferably coded as '9'.
- Ambiguous values (e.g. two boxes are ticked for a single dimension) should be treated as missing values.
- This example is for the EQ-5D-5L Paper Self-Complete. Instructions for the interview and proxy versions are provided with those instruments.

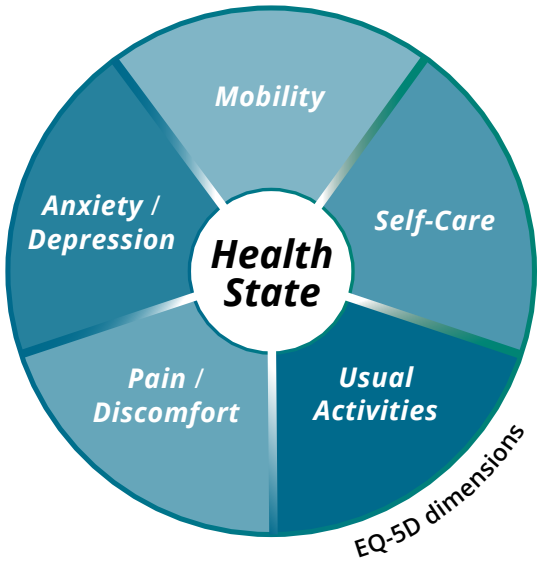
2.1 / What is a health state?

Each of the five dimensions comprising the EQ-5D descriptive system is divided into five levels of perceived problems:

LEVEL 1: indicating no problem
LEVEL 2: indicating slight problems
LEVEL 3: indicating moderate problems
LEVEL 4: indicating severe problems
LEVEL 5: indicating unable to/extreme problems

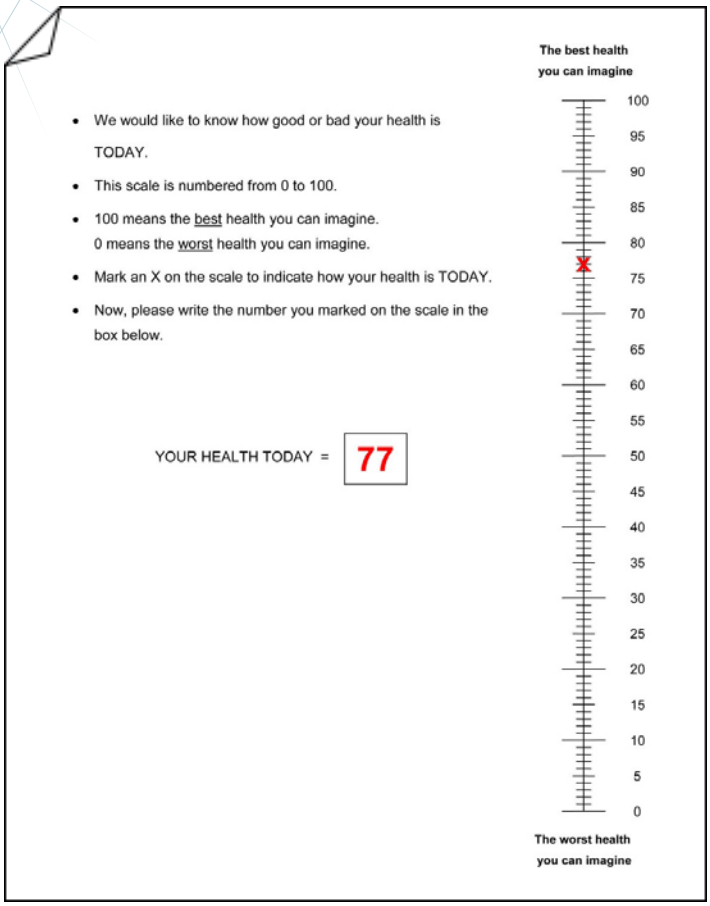
A unique health state is defined by combining one level from each of the five dimensions.

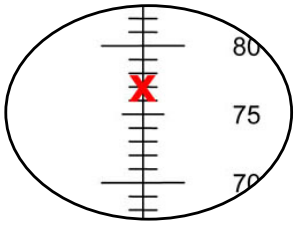
A total of 3125 possible health states is defined in this way. Each state is referred to by a 5-digit code. For example, working clockwise from the top of the diagram, state 12345 indicates no problems with mobility, slight problems with washing or dressing, moderate problems with doing usual activities, severe pain or discomfort and extreme anxiety or depression, while state 11111 indicates no problems on any of the five dimensions.



3. Scoring the EQ VAS

This example from the EQ-5D-5L Paper Self-Complete version shows how the EQ VAS is scored.





For example,
the response above
should be coded as 77

Notes:

- For this example, the response should be coded as 77
- Missing values should be coded as '999'.
- If there is a discrepancy between where the respondent has placed the X and the number he/she has written in the box, administrators should use the number in the box (this is only relevant for the Paper Self-Complete version).

4. Converting EQ-5D-5L states to an index value

4.1 / Deriving an EQ-5D index value

EQ-5D-5L health states can be summarised using the 5-digit code (see Section 2.1) or represented by a single summary number (**index value**)*, which reflects how good or bad a health state is according to the preferences of the general population of a country/region. Index values are a major feature of the EQ-5D instrument, facilitating the calculation of quality-adjusted life years (QALYs) that are used to inform economic evaluations of healthcare interventions. The preferences of the general population of a country/region for different health states represent the societal perspective which, in general, is considered the preferred perspective in health economic analysis.[11–13]

An EQ-5D summary index is derived by applying a formula that attaches values (weights) to each of the levels in each dimension. The index is calculated by deducting the appropriate weights from 1, the value for full health (i.e. state 11111). The collection of index values (weights) for all possible EQ-5D health states is called a **value set**. Most EQ-5D value sets have been obtained from a standardised valuation exercise, in which a representative sample of the general population in a country/region is asked to place a value on EQ-5D health states. The standardised valuation study protocol, **EQ-VT**, was developed by the EuroQol Group to create standard value sets for the EQ-5D-5L. This protocol is based on the use of the composite time trade-off (cTTO) valuation technique, supplemented by a discrete-choice experiment (DCE). Using value sets produced with the EuroQol Group's standardised valuation technology, EQ-VT ensures that results are derived using the most state-of-the-art valuation techniques while also facilitating international comparability.

Note: It is advisable to contact authorities about national value set requirements.

4.2 / Standard EQ-5D-5L value sets

At the time of publication (September 2019), EQ-5D-5L valuation research using EQ-VT has been undertaken in 34 countries around the world. The latest status of the EQ-5D-5L valuation studies can be viewed on the EuroQol website and a list of value sets published as of September 2019 is provided in Table 1.
An updated list of available value sets can be found on the EuroQol website. Note, to obtain a value set please contact the valuation study authors.

If a standard EQ-5D-5L value set is not available for your country, an option may be to select an EQ-5D-5L value set for a country/region that most closely approximates yours. Alternatively, if an EQ-5D-3L value set is available, you can choose to use a so-called 'crosswalk' value set — a value set created for the EQ-5D-3L and then adapted to fit the EQ-5D-5L descriptive system. More information about crosswalk value sets can be found on the EuroQol website and a brief overview of the crosswalk project is provided in the following sections.

* Many different terms are in use for these index values, such as preference weights, preference-based values, utilities, QALY weights, etc. Here, we use the term 'index value'.

Table 1 / **List of available (published) standard EQ-5D-5L value sets and status of ongoing valuation studies by country (as of September 2019)**

Country/ Region	Valuation study status	Year of data Collection	N	Valuation Method
AFRICA				
Egypt	Ongoing	2019		EQ-VT v2.0
Ethiopia	Completed[a]	2018	1050	EQ-VT v2.0
ASIA				
China[14]	Published	2012	1271	EQ-VT v1.0
Hong Kong[15]	Published	2014	1033	EQ-VT v1.1
India	Ongoing	2019		EQ-VT v2.1[b]
Indonesia[16]	Published	2015	1054	EQ-VT v2.0
Japan[17]	Published	2013	1026	EQ-VT v1.1
Malaysia[18]	Published	2016	1137	EQ-VT v2.0
Philippines	Completed	2017		EQ-VT v2.1
Singapore	Completed	2014-2015		EQ-VT v2.0
South Korea[19]	Published	2013	1080	EQ-VT v2.0
Taiwan[20]	Published	2017	1000	EQ-VT v2.0
Thailand[21]	Published	2014	1207	EQ-VT v1.1
Vietnam	Completed			EQ-VT v2.1
EUROPE				
Belgium	Ongoing	2018-2019		EQ-VT v2.1
Denmark	Ongoing	2018-2019		EQ-VT v2.1
England[22]	Published	2012	996	EQ-VT v1.0
France	Completed	2018		EQ-VT v2.1
Germany[23]	Published	2015	1158	EQ-VT v2.0
Hungary	Completed	2018		EQ-VT v2.1
Ireland[24]	Published	2015-2016	1160	EQ-VT v2.0
Netherlands[25]	Published	2012	1003	EQ-VT v1.0
Norway	Ongoing			
Poland[26]	Published	2016	1252	EQ-VT v2.0
Portugal[27]	Published	2015-2016	1451	EQ-VT v2.0
Romania	Ongoing	2018-2019		EQ-VT v2.1
Spain[28]	Published	2012	1000	EQ-VT v1.0
Sweden	Ongoing			
NORTH AND SOUTH AMERICA				
Canada[29]	Published	2012	1073	EQ-VT v1.0
Mexico	Ongoing	2019		EQ-VT v2.1
Peru	Completed	2018-2018	1000 (DCE=1000; TTO=300)[b]	EQ-VT v2.1 'light'
Uruguay[30]	Published	2013	794	EQ-VT v1.1
USA[31]	Published	2017	1062	EQ-VT v2.0
OCEANIA				
Australia	Completed	2017	300[b]	EQ-VT v2.0 'light'

[a] Results for 'completed' studies were not available at the time of publication of this User Guide; please check the EuroQol website for the latest status of these studies.
[b] The experimental design of the valuation study was modified to be optimal for the amended sample size. Further details can be obtained from the EuroQol office.

DCE, discrete-choice experiment; EQ-VT, standardised valuation study protocol; TTO, time trade-off.

4.3 / The EQ-5D-5L crosswalk project

The EuroQol Group coordinated a study that administered both the 3L and 5L versions of the EQ-5D, in order to develop a 'crosswalk' between the EQ-5D-3L value sets and the new EQ-5D-5L descriptive system, resulting in crosswalk value sets for the EQ-5D-5L. A total of 3691 respondents completed both the EQ-5D-3L and EQ-5D-5L across six countries: Denmark, England, Italy, the Netherlands, Poland and Scotland. Different subgroups were targeted, and in most countries, a screening protocol was implemented to ensure that a broad spectrum of levels of health would be captured across the dimensions of EQ-5D for both the 5L and 3L descriptive systems. Several methods were consequently tested to optimise the link function between the two descriptive systems. A scientific report by van Hout and colleagues (2012) describing the mapping methodology behind the study in detail has been published.[32] A more detailed description of the crosswalk model and methodology also can be downloaded from the EuroQol website.

4.4 / Crosswalk value sets for the EQ-5D-5L

The crosswalk link function resulting from the research by van Hout and colleagues (2012)[32] can be used to calculate index values for EQ-5D-5L, using the individual responses to the EQ-5D-5L descriptive system and the existing value sets for the EQ-5D-3L. Value sets have been derived for EQ-5D-3L in a number of countries using either the visual analogue scale technique or the time trade-off valuation techniques. The list of currently available EQ-5D-3L value sets is presented on the EuroQol website. Most of the EQ-5D-3L value sets have been obtained using a representative sample of the general population, thereby ensuring that they represent the societal perspective. A tool, the 'EQ-5D-5L Crosswalk Index Value Calculator', that calculates the crosswalk index values for the EQ-5D-5L dimension scores is available for download on the EuroQol website.

Crosswalk value sets for the EQ-5D-5L are currently available for the following countries: Denmark, France, Germany, Japan, the Netherlands, Spain, Thailand, UK, USA and Zimbabwe. The actual index values can be downloaded from the EuroQol website.

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FURTHER INFORMATION ON VALUE SETS

- For more information on how to choose a value set, see the EuroQol website.
- For anyone working with EQ-5D data, an essential guide to the use of the EuroQol Group's value sets can be found in Vol. 2 of the EuroQol Group Monograph series, *EQ-5D Value Sets: Inventory, Comparative Review and User Guide* (Springer, 2006), available at https://euroqol.org/publications/books.
- Documents containing the scoring algorithms, information on the valuation studies, tables of values for all 3125 health states and syntax files[a] may be requested from the EuroQol office.

[a] *A syntax file is a computer program that can be run using statistical software to automatically calculate the values for the EQ-5D health states stored in a database.*

5. Organising EQ-5D-5L data

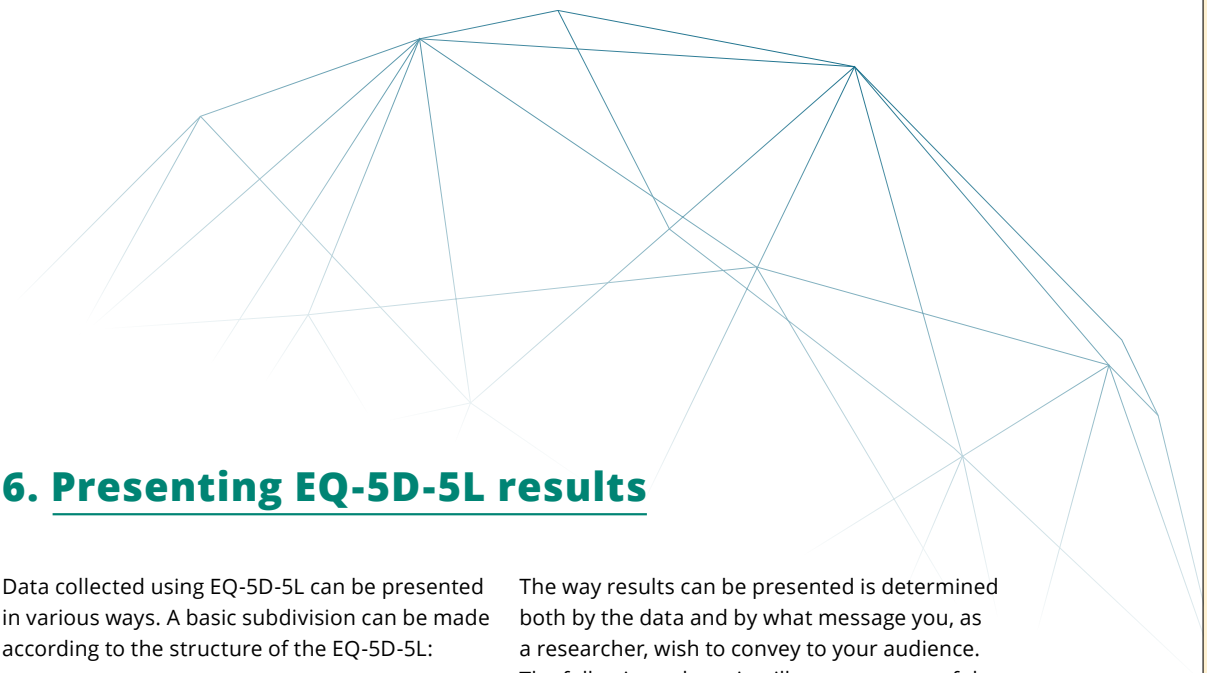
Data collected using EQ-5D-5L can be entered in a database according to the following schema:

Variable Name	ID	Sex	Age	EDU	Country	Year	Mobility
Variable description	Patient ID number	1 = Male 2 = Female 9 = Missing value	999 = Missing value	1 = Low 2 = Medium 3 = High 9 = Missing value	Country where data was collected	Year in which data was collected	1 = No problems 2 = Slight problems 3 = Moderate problems 4 = Severe problems 5 = Unable to 9 = Missing value
Data row 1	1001	1	43	1	UK	2011	4
Data row 2	1002	2	24	2	UK	2011	2

Variable Name	Self-care	Activity	Pain	Anxiety	State	EQ_VAS
Variable description	1 = No problems 2 = Slight problems 3 = Moderate problems 4 = Severe problems 5 = Unable to 9 = Missing value	1 = No problems 2 = Slight problems 3 = Moderate problems 4 = Severe problems 5 = Unable to 9 = Missing value	1 = No pain 2 = Slight pain 3 = Moderatly pain 4 = Severe pain 5 = Extreme pain 9 = Missing value	1 = Not anxious 2 = Slightly anxious 3 = Moderately anxious 4 = Severely anxious 5 = Extremely anxious 9 = Missing value	5-digit code for EQ-5D-5L	999 = Missing value
Data row 1	1	3	2	5	41325	63
Data row 2	1	1	1	1	21111	90

Notes:

- The variable names are just examples. However, the variables for the five dimensions of the EQ-5D descriptive system should be named 'mobility', 'self-care', 'activity', 'pain' and 'anxiety'.
- A respondent's rating on EQ VAS is to the nearest whole number.



6. Presenting EQ-5D-5L results

Data collected using EQ-5D-5L can be presented in various ways. A basic subdivision can be made according to the structure of the EQ-5D-5L:

1. Presenting results from the EQ-5D-5L descriptive system as a health profile
2. Presenting results of the EQ VAS as a measure of overall self-rated health status
3. Presenting results from the EQ-5D-5L index value.

The way results can be presented is determined both by the data and by what message you, as a researcher, wish to convey to your audience. The following subsection illustrates some of the basic ways of presenting EQ-5D data.

6.1/Health profiles

Reporting descriptive statistics on patient-reported outcomes (PRO) data can be very insightful. In patient samples, it can identify which dimensions of health are most affected by a given condition or treatment; in population health surveys, it can provide an overview of the frequency of problems across dimensions and, in repeated surveys, show their evolution over time.

When reporting data, it is important to begin by describing the number and percentage of patients reporting each level of problem on each dimension of the EQ-5D. For example, Table 2 shows EQ-5D-5L data from a recent survey of 6800 individuals who were representative of the Lombardy (Italy) general adult population for age, gender and geographic distribution.[33] The study authors also reported the proportion of patients with a full health state of 11111 (38.0%), as well as stratifying the results by age and gender (data not presented here). Tables can also be broken down for other relevant subgroups — for example, by treatment arm, age group or sex — and/or by study visit, e.g. before/after treatment.

Table 2 / **EQ-5D-5L frequencies and proportions reported by dimension and level**[33]

	MOBILITY n (%)	SELF-CARE n (%)	USUAL ACTIVITIES n (%)	PAIN / DISCOMFORT n (%)	ANXIETY / DEPRESSION n (%)
Level 1 (No prolems)	5727 (84.2)	6406 (94.2)	5770 (84.9)	3592 (52.8)	4196 (61.7)
Level 2 (Slight prolems)	614 (9.0)	214 (3.1)	626 (9.2)	2046 (30.1)	1747 (25.7)
Level 3 (Moderate prolems)	353 (5.2)	132 (1.9)	311 (4.6)	1018 (15.0)	757 (11.1)
Level 4 (Severe prolems)	86 (1.3)	31 (0.5)	65 (1.0)	123 (1.8)	56 (0.8)
Level 5 (Extreme prolems/ unable to do)	20 (0.3)	17 (0.3)	28 (0.4)	21 (0.3)	44 (0.6)
Total	6800 (100)	6800 (100)	6800 (100)	6800 (100)	6800 (100)

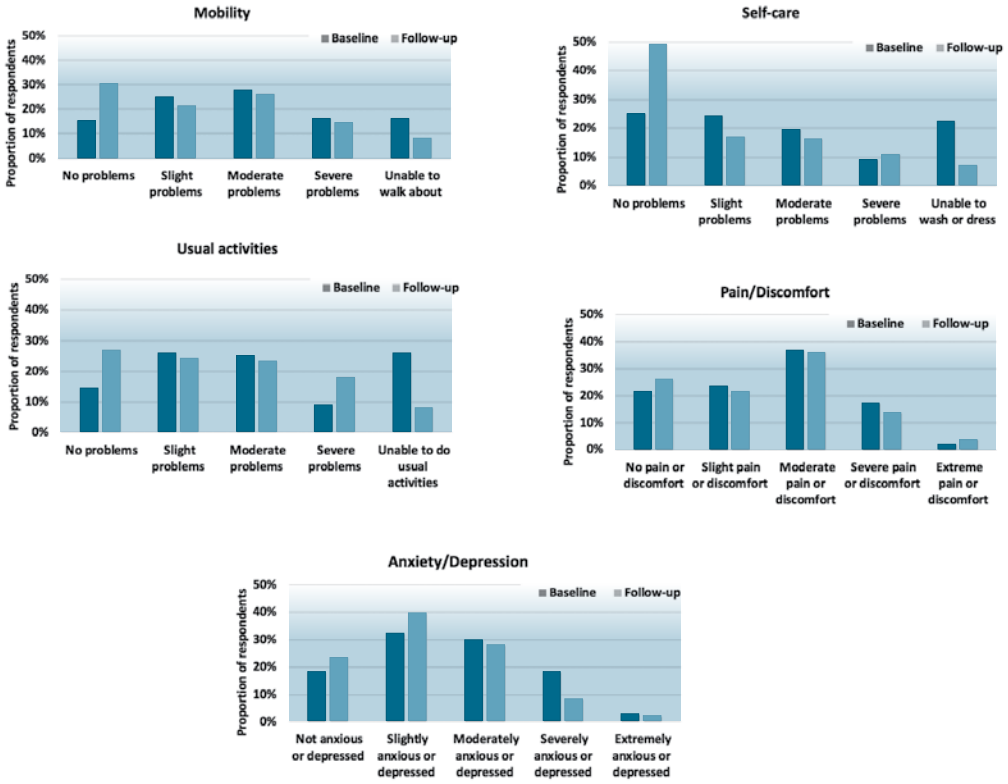
Note: Sometimes it is more convenient to dichotomise the EQ-5D levels into 'no problems' (level 1) and 'any problems' (levels 2, 3, 4 and 5), thereby changing the profile into frequencies of reported problems.

Data can also be presented to show changes in health over time. For example, in a single-centre observational longitudinal cohort study of patients (n=112) with stroke in Poland, the EQ-5D-5L was administered on two separate occasions.[34] The initial survey took place during index hospitalisation, before discharge. The second survey was conducted after an initial post-stroke recovery phase about 4 months later, in outpatient clinics, neurological rehabilitation departments or the patients' own homes. Table 3 shows significant differences in the distribution of responses to the self-care and usual activities dimensions of the EQ-5D-5L ($p<0.001$ and 0.001, respectively). It can also be helpful to report this information graphically (Figure 2).

Table 3 / **Distribution of EQ-5D-5L dimension responses at baseline and at follow-up**[34]

Dimension	Baseline n (%)	Follow-up n (%)	P Value
Mobility			
No problems	17 (15.2)	34 (30.4)	**0.057**
Slight problems	28 (25.0)	24 (21.4)	
Moderate problems	31 (27.7)	29 (25.9)	
Severe problems	18 (16.1)	16 (14.3)	
Unable to walk about	18 (16.1)	9 (8.0)	
Self-care			
No problems	28 (25.0)	55 (49.1)	**< 0.001**
Slight problems	27 (24.1)	19 (17.0)	
Moderate problems	22 (19.62)	18 (16.1)	
Severe problems	10 (8.9)	12 (10.7)	
Unable to wash or dress	25 (22.3)	8 (7.1)	
Usual activities			
No problems	16 (14.3)	30 (26.8)	**0.001**
Slight problems	29 (25.9)	27 (24.1)	
Moderate problems	28 (25.0)	26 (23.2)	
Severe problems	10 (8.9)	20 (17.9)	
Unable to do usual activities	29 (25.9)	9 (8.0)	
Pain/discomfort			
No pain/discomfort	24 (15.2)	29 (25.9)	**NS**
Slight pain/discomfort	26 (23.2)	24 (21.4)	
Moderate pain/discomfort	41 (36.6)	40 (35.7)	
Severe pain/discomfort	19 (17.0)	15 (13.4)	
Extreme pain/discomfort	2 (1.8)	4 (3.6)	
Anxiety/drepression			
Not anxious/depressed	20 (17.9)	26 (23.2)	**NS**
Slightly anxious/depressed	36 (32.1)	44 (39.3)	
Moderately anxious/depressed	33 (29.5)	31 (27.7)	
Severely anxious/depressed	20 (17.9)	9 (8.0)	
Extremely anxious/depressed	3 (2.7)	2 (1.8)	

Figure 2 / **Proportion of responses by level of severity for EQ-5D-5L dimensions at baseline and at follow-up**[34]



Although very useful information is contained in tables like Table 3, they can be hard to read; an overall summary is sometimes helpful. One way of simplifying the information is based on the principles of a Pareto improvement in Welfare Economics — the Pareto Classification of Health Change (PCHC).[35] With this approach, an EQ-5D health state is deemed to be 'better' than another if it is better on at least one dimension and is no worse in any other dimension. An EQ-5D health state is deemed to be 'worse' than another if it is worse in at least one dimension and is no better in any other dimension. Using that principle to compare a patient's EQ-5D health states between any two time periods, there are only four possibilities:

- Their health state is better
- Their heath state is worse
- Their health state is exactly the same
- The changes in health are 'mixed': better on one dimension, but worse on another.

6.2/EQ VAS

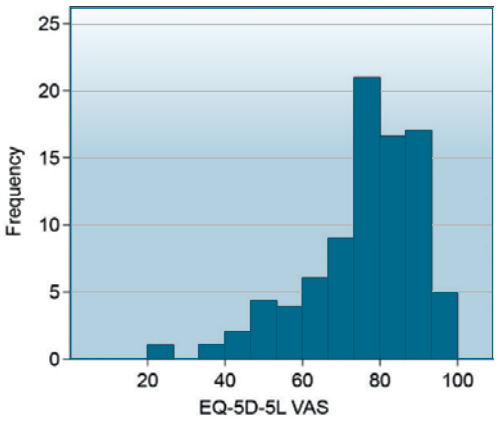
As described earlier, the EQ VAS is a 0—100 scale where patients are asked to indicate their overall health on the day of questionnaire completion. It is conceptually different from the EQ-5D index which is a value attached to an EQ-5D profile according to a set of weights that reflect, on average, people's preferences about how good or bad the state is. The EQ VAS represents the patient perspective, whereas most values sets represent the societal perspective (i.e., what the general population thinks about the value of the health state). Choosing which perspective is most relevant depends on the research question. As a rule of thumb, the societal perspective is mostly used in health economics, while the respondent's perspective is used in clinical assessment of the patient and population surveys.

EQ VAS data should be presented using a measure of central tendency and a measure of dispersion. This could be the mean value and the standard deviation (SD) or, if the data are skewed, the median values and the interquartile range (IQR). A couple of examples are given below.

- In a large (n=1296) EQ-5D-5L valuation study in China, the mean (SD) EQ VAS was reported as 86.0 (11.4).[36]
- In an e-survey of patients (n=337) across 30 countries with tenosynovial giant cell tumour, it was reported that the median (IQR) was 75 (65–85) for localised and 75 (56.5-85) for diffuse type tumours.[37]

EQ VAS data can also be presented graphically, such as in frequency charts (Figure 3).

Figure 3 / EQ-5D-5L VAS frequency distribution (hypothetical data)



6.3/EQ-5D index

Information about the EQ-5D index, derived using a value set, can be presented in much the same way as the EQ VAS data, i.e. using measures of central tendency and dispersion, such as mean values and the SD (or standard error). If the data are skewed, the median values and the 25th and 75th percentiles could be presented. Note, when reporting index values, a maximum of three decimal places is usually sufficient.

Table 4 provides an example where index values are reported for a representative sample of the Spanish general population (n=21,007) using data from the Spanish National Health Survey 2011–2012.[38] The index values are reported by various sociodemographic factors and clinical characteristics in the paper.

Table 4 / **Selected study sample characteristics, EQ-5D-5L male and female population norms**[38]

	EQ-5D-5L INDEX	
	Mean	SD
Overall	0.897	0.212
GENDER		
Female	0.867	0.238
Male	0.931	0.171
AGE GROUP		
15–17	0.983	0.115
18–29	0.978	0.101
30–39	0.971	0.110
40–49	0.959	0.111
50–59	0.930	0.166
60–69	0.922	0.172
70–79	0.871	0.214
80–89	0.744	0.315
≥90	0.645	0.304
MARITAL STATUS		
Single	0.952	0.150
Married	0.928	0.174
Divorced/separated	0.930	0.165
Widowed	0.836	0.239
SMOKING STATUS		
Yes	0.903	0.199
No	0.991	0.050
NET MONTHLY INCOME OF HOUSEHOLD (€)		
<550	0.897	0.209
551–1300	0.903	0.195
1301–2250	0.947	0.151
2251–3450	0.961	0.146
≥3451	0.972	0.093

Table 5 gives a hypothetical example of how to present EQ-5D index results for an intervention study. The improvement in health state utility associated with treatment with Drug A versus Drug B was 0.08 ($p<0.05$) at Week 12.

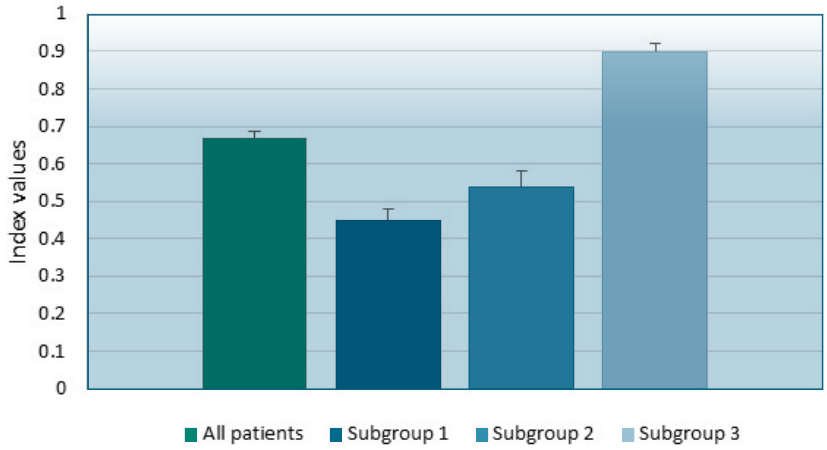
Data can also be presented graphically; a hypothetical example is presented in Figure 4 where the group highest mean health status, using the EQ-5D-5L index, is subgroup 3. Subgroup 1 reported the worst health. The differences between all subgroups were statistically significant ($p<0.05$).

Table 5 / **Impact of treatment on EQ-5D-5L index score (hypothetical data)**

Visit	Drug A		Drug B		p-value[a]
	N	Mean (SD)	N	Mean (SD)	
Baseline	229	0.59 (0.30)	227	0.60 (0.28)	0.6345
Week 12	194	0.57 (0.32)	186	0.65 (0.29)	0.0149

[a] Using *t*-test.

Figure 4 / **Mean EQ-5D-5L index values and 95% confidence intervals for the total patient population and three subgroups (hypothetical data)**



ANALYSIS OF UTILITY DATA FOR ECONOMIC EVALUATION

When analysing data to inform an economic evaluation, the approach will generally need to be different from an analysis that has been undertaken for regulatory purposes – i.e. which reports a comparison between treatment arms. Typically, EQ-5D data will be analysed to estimate the difference between health states (defined in an economic model) or the effect of specific events (e.g. a stroke, exacerbation or relapse). Such an analysis should also control for the effect of treatment arm, but the treatment arm may not be the primary focus of the analysis. For further insight on this topic, please refer to the ISPOR Good Research Practices Task Force report on 'Estimating Health-State Utility for Economic Models in Clinical Studies' by Wolowacz et al, 2016.[39]

Example text for describing the EQ-5D and reporting and analysing EQ-5D data for study protocols/proposals

Study protocols and project proposals often require information to be included describing the EQ-5D instrument and how the results will be reported and analysed. Below is an example outline of the kind of information that could be provided on the EQ-5D-5L for an intervention study.

About the EQ-5D

- The EQ-5D-5L[1] is a widely used generic measure of health status consisting of two parts. The first part (the descriptive system) assesses health in five dimensions (MOBILITY, SELF-CARE, USUAL ACTIVITIES, PAIN / DISCOMFORT, ANXIETY / DEPRESSION), each of which has five levels of response (no problems, slight problems, moderate problems, severe problems, extreme problems/unable to). This part of the EQ-5D questionnaire provides a descriptive profile that can be used to generate a health state profile. For example, a patient in health state 12345 would have no problems with mobility, slight problems with self-care (washing or dressing), moderate problems with doing usual activities, severe pain or discomfort and extreme anxiety or depression. Each health state can potentially be assigned a summary index score based on societal preference weights for the health state. These weights, sometimes referred to as 'utilities', are often used to compute QALYs for use in health economic analyses. Health state index scores generally range from less than 0 (where 0 is the value of a health state equivalent to dead; negative values representing values as worse than dead) to 1 (the value of full health), with higher scores indicating higher health utility. The health state preferences often represent national or regional values and can therefore differ between countries/regions. The second part of the questionnaire consists of a visual analogue scale (VAS) on which the patient rates his/her perceived health from 0 (the worst imaginable health) to 100 (the best imaginable health). The EQ-5D questionnaire is cognitively undemanding, taking only a few minutes to complete. Instructions to patients are included in the questionnaire.

Reporting and analysis of results

- A health profile will be generated by visit and by treatment. Summary statistics will be derived, including numbers of patients and proportions of categorical responses for the five EQ-5D dimensions.
- A health state index score will be calculated from individual health profiles using [insert country/region specific value set and reference here – where a value set is not available for your country/region, it may be possible to use a value set for a country/region that most closely approximates yours or use a crosswalk value set[a]]. Mean, standard deviation (SD), minimum, median, and maximum scores will be provided for the study population by visit and by treatment.
- The EQ VAS score (between 0 and 100) will be summarised using mean, SD, minimum, median and maximum scores by visit and by treatment.
- For the health state index and EQ VAS scores, mean, SD, minimum, median and maximum will be provided for change from baseline to [enter questionnaire assessment time points here, e.g. Week 12, Week 24] and [final study assessment, e.g. Week 52].
- The type of model used and the covariates and fixed effects will be study-dependent. As an example, an ANCOVA model could be conducted for the changes from baseline to [assessment time points], with country and treatment as fixed effects and baseline as a covariate. In this example, significance of change within each treatment group and significance of the difference between the treatment groups would be reported.

[a] *See* **EuroQol website** *section on choosing a value set, for more information.*

7. EQ-5D-5L translations and modes of administration

7.1 / EQ-5D-5L translations

The EQ-5D-5L (Paper Self-Complete version) is available in more than 150 languages.
All translation / adaptations of EQ-5D are produced using a standardised translation protocol that conforms to internationally recognised guidelines. These guidelines aim to ensure equivalence to the English 'source' version and involve a forward/backward translation process and cognitive debriefing.[40] New translations can be produced on request.

The EuroQol office manages the production of new translations and in general, translation costs are covered by the client requesting a translation.

For more information on the EQ-5D translation process, consult the **EuroQol website** or contact the **EuroQol office**. See the next section regarding the availability of EQ-5D-5L translations for different modes of administration.

7.2 / Modes of administration

The EQ-5D-5L is available in a wide range of modes of administration (Table 6).

Table 6 / **Language versions available for various modes of administration of the EQ-5D-5L**

Modes of administration	Total number of languages versions available
SELF-COMPLETE VERSIONS	
Paper	>170
PDA/Smartphone	>200
Tablet	>110
Laptop/Desktop	>150
REDCap Platform [a]	>40
Limesurvey Platform [b]	>5
Castor EDC Platform [c]	>2
INTERVIEW VERSIONS	
Interviewer Administration [d]	>3
Face-to-face	>6
Telephone	>90
PROXY VERSIONS	
Proxy version 1 [e]	>150
Proxy version 2 [f]	>40
INTERACTIVE VOICE RESPONSE SYSTEM VERSION	
IVR system version	>30

[a] REDCap is a secure web application for building and managing online surveys and databases.
[b] LimeSurvey is an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system.
[c] Castor EDC is a cloud-based Electronic Data Capture platform that enables commercial and non-commercial researchers to easily capture high quality, reusable data from any source in real-time.
[d] Interviewer Administered (IA) version was developed for use either in face-to-face or telephone/computer interviews when participants are either unable to read or write or unable to be physically present for the interview. May be used interchangeably with existing Telephone and Face-to-face versions.
[e] Proxy version 1: The caregiver (the proxy) is asked to rate the patient's health in their (the proxy's) opinion.
[f] Proxy version 2: The caregiver (the proxy) is asked to rate how they (the proxy) think the patient would rate his/her own health, if the patient were able to communicate it.

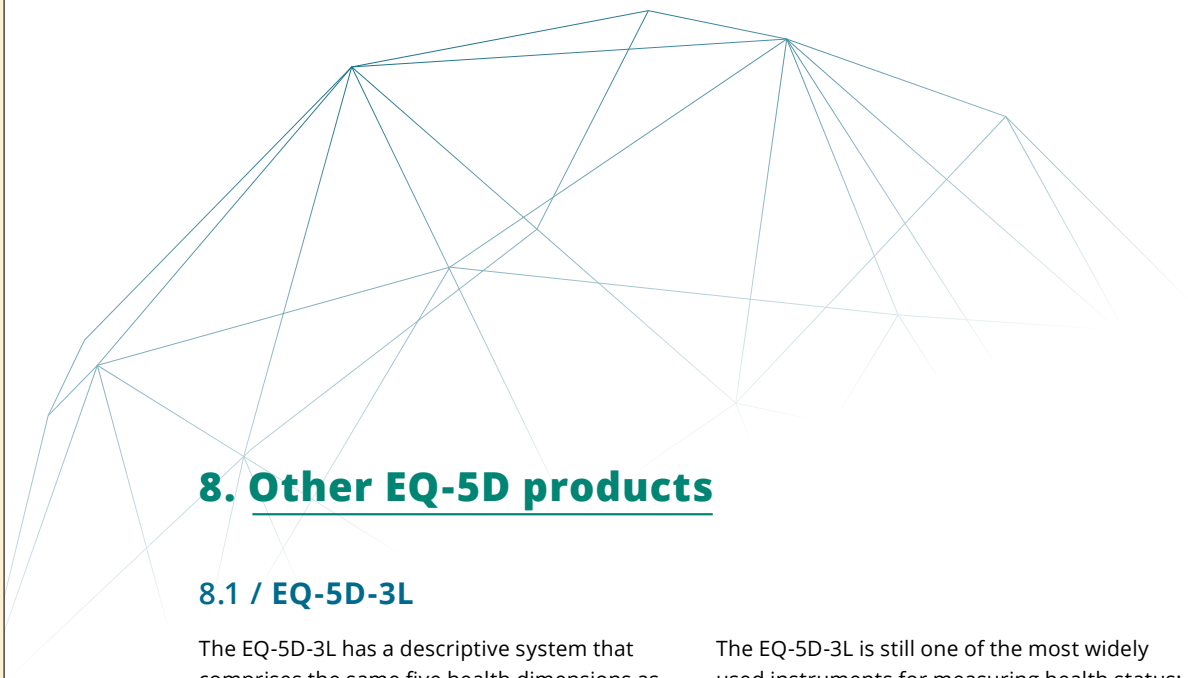
Note: To find out whether an EQ-5D-5L language version is available for your country / region, please consult the relevant mode of administration section of the **EuroQol website**. If a language version is not currently available, please contact the **EuroQol office**.

EQ-5D MODULAR VERSIONS

Previously, EQ-5D would have to be hosted on EuroQol's dedicated server. EQ-5D can now also be hosted on your own server, the REDCap, the LimeSurvey or the Castor EDC platform. These EQ-5D modular versions are now available as ready-to-use surveys that do not require screenshot review by EuroQol.

- **REDCap:** a web application for building and managing online surveys and databases. It is mainly used in academic research.
- **LimeSurvey:** an open-source survey software solution. Available as a professional SaaS solution or as a self-hosted system.
- **Castor EDC:** a cloud-based Electronic Data Capture platform that enables commercial and non-commercial researchers to easily capture high-quality, reusable data from any source in real time.

For further information, please see the **website** or contact the **EuroQol office**.



8. Other EQ-5D products

8.1 / EQ-5D-3L

The EQ-5D-3L has a descriptive system that comprises the same five health dimensions as in the EQ-5D-5L, but each dimension has three levels: no problems, some problems, extreme problems. The EQ-5D-3L preceded the 5L version of the EQ-5D and was introduced in 1990.

The EQ-5D-3L is still one of the most widely used instruments for measuring health status; it is currently available in more than 180 different language versions (for the self-complete versions), across several modes of administration (Table 7).

Table 7 / **EQ-5D-3L available modes of administration**

Self-complete versions	**Interview versions**
• Paper	• Interviewer Administered (IA)
• PDA/Smartphone	• Face-to-face
• Tablet	• Telephone
• Laptop/Desktop	**Proxy versions**
• REDCap platform	**Interactive Voice Response system version**
• LimeSurvey platform	
• Castor EDC platform	

Note: For more information on the EQ-5D-3L and to see whether an EQ-5D-3L version exists for your country/region, please consult the **EuroQol website**. An EQ-5D-3L user guide is also available on the **EuroQol website**.

8.2 / EQ-5D-Y (Youth)

The EQ-5D-Y is a child-friendly version of the EQ-5D-3L questionnaire that was developed specifically for children and adolescents aged 8–15 years (Table 8). It can also be used in paediatric studies that include respondents up to 18 years, if it is preferred to just use a single EQ-5D version in the study.

Table 8 / **The age range of users of the EQ-5D-Y version**

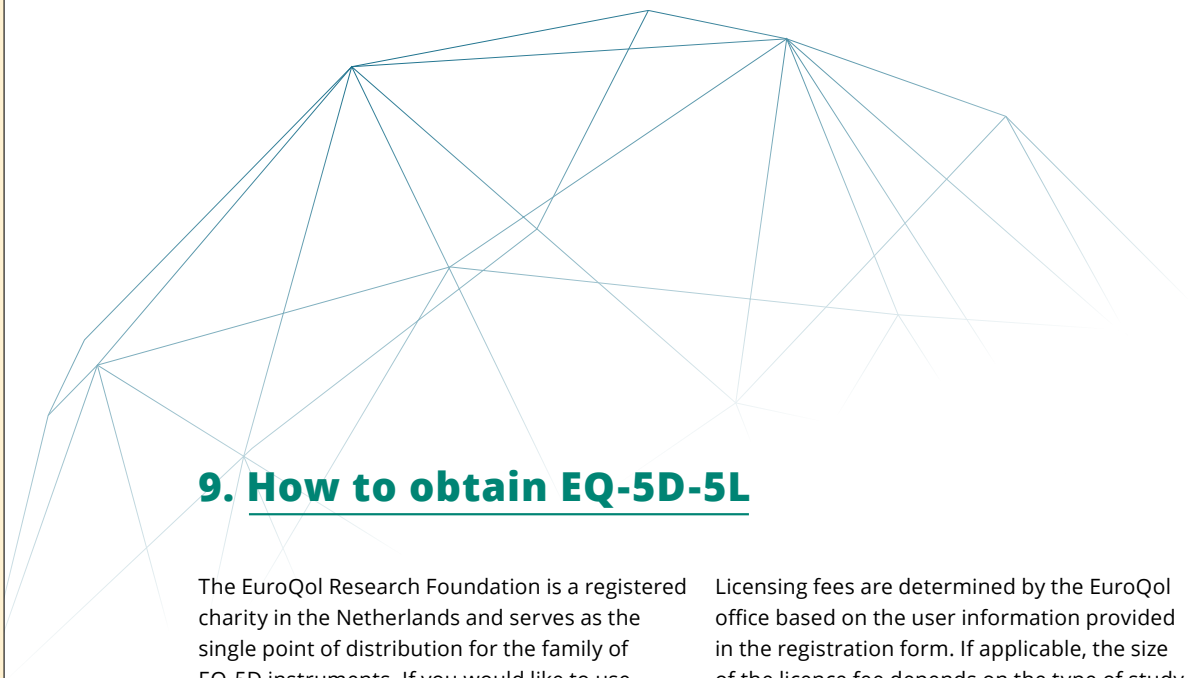
Age 0–7	**No EQ-5D-Y for youngest children** For children aged 4–7, a proxy version can be used.
Age 8–11	**EQ-5D-Y** A youth version is more understandable for children.
Age 12–15	**Overlapping area: both Youth and Adult EQ-5D versions can be used** Generally, EQ-5D-Y is recommended. However, depending on study design, using the EQ-5D adult version might be possible.
Age 16 and older	**Adult version** Possible exception: a study only with children up to 18 years; in this case EQ-5D-Y for older children would be recommended in order to have only one EQ-5D version in the study. Switching to the adult version could disrupt continuity, as the adult and child versions are two different instruments.

Self-complete and proxy versions of the EQ-5D-Y are available (Table 9). The self-complete version is now available in more than 50 language versions. Research is ongoing, partly funded by the EuroQol Research Foundation, to derive EQ-5D-Y value sets for use in children and adolescents. Please consult the EuroQol website for the latest developments on EQ-5D-Y valuation research.

Table 9 / **EQ-5D-Y available modes of administration**

Self-complete versions	Proxy versions
• Paper	• Face-to-face
• PDA/Smartphone	• Telephone
• Tablet	

Note: If you would like to know whether there is an EQ-5D-Y version appropriate for your country/region, please consult the **EuroQol website**. A user guide for the EQ-5D-Y is also available on the **EuroQol website**.



9. How to obtain EQ-5D-5L

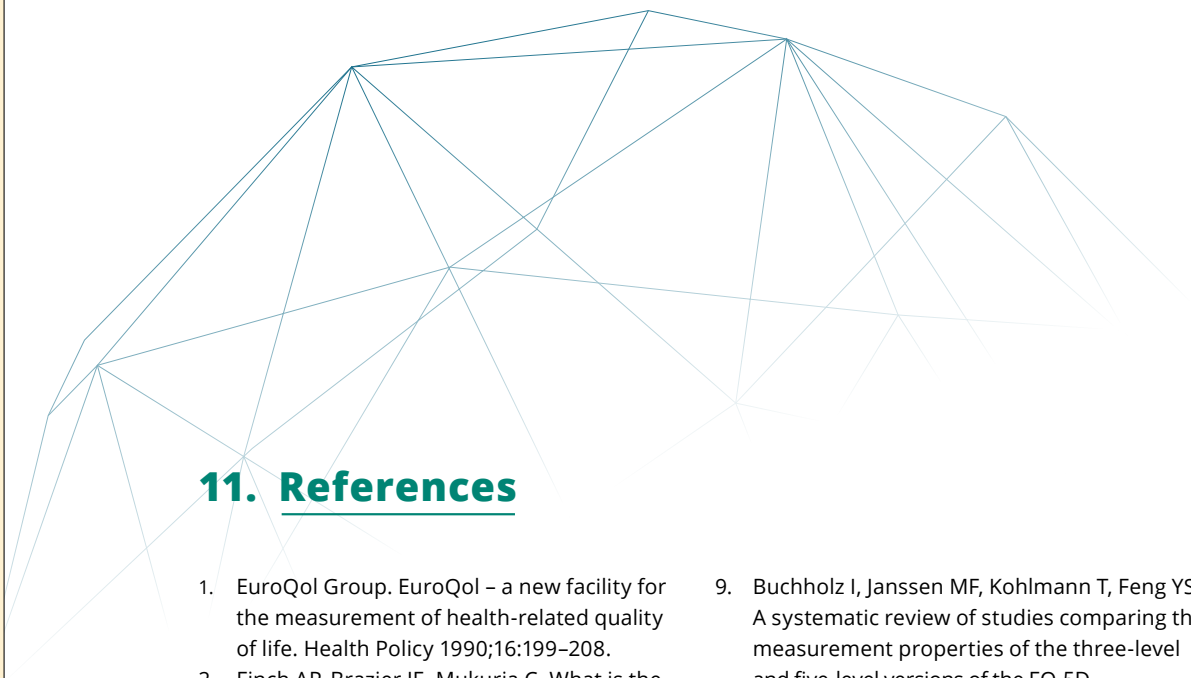
The EuroQol Research Foundation is a registered charity in the Netherlands and serves as the single point of distribution for the family of EQ-5D instruments. If you would like to use the EQ-5D in your study/trial/project, please complete the registration form on the **EuroQol website**. Note, you are not obliged to purchase the EQ-5D by registering. The EuroQol office will then e-mail you with details of the terms and conditions for use, including licensing fees if applicable. Default timelines for EuroQol business processes for different elements of the licensing process are provided on the **EuroQol website**.

Licensing fees are determined by the EuroQol office based on the user information provided in the registration form. If applicable, the size of the licence fee depends on the type of study, funding source, sample size and number of requested EQ-5D versions and languages.
The EQ-5D user licence policy is available on the **EuroQol website**. Please note that where fees are charged, these allow the EuroQol Research Foundation to fund activities in line with its vision and mission as described on the **EuroQol website**.

10. Additional resources on the EuroQol website

Throughout this User Guide, weblinks to relevant resources on the EuroQol website have been provided. Here is a selection of additional web resources that the reader may find useful:

Answers to frequently asked questions	https://euroqol.org/support/faqs/
EQ-5D terms explained	https://euroqol.org/support/terminology/
Key EQ-5D-5L references	https://euroqol.org/publications/key-euroqol-references/eq-5d-5l/
EQ-5D books	https://euroqol.org/publications/books/
EQ-5D working papers	https://euroqol.org/publications/working-papers/
Explanation of EQ-5D version numbering and quality control	https://euroqol.org/support/quality-control/



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EQ-5D

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Rockwood frailty scale

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.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

DALHOUSIE UNIVERSITY
Inspiring Minds

The Barthel ADL Index

THE BARTHEL INDEX

Patient Name: _____
Rater Name: _____
Date: _____

Activity	Score
FEEDING 0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	_____
BATHING 0 = dependent 5 = independent (or in shower)	_____
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	_____
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	_____
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	_____
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	_____
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	_____
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	_____
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	_____
STAIRS 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	_____

TOTAL (0–100): _____

Provided by the Internet Stroke Center — www.strokecenter.org

The Barthel ADL Index

The Barthel ADL Index: Guidelines

1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

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Copyright Information

Self-Efficacy for Managing Chronic Disease 6-item scale

Self-Efficacy for Managing Chronic Disease 6-item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

2. How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

3. How confident do you feel that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

4. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

5. How confident do you feel that you can the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

6. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the

1

Self-Efficacy for Managing Chronic Disease 6-item scale

scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

Characteristics

Tested on 605 subjects with chronic disease
.

No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	1-10	5.17	2.22	.91	NA

Source of Psychometric Data

Stanford/Garfield Kaiser Chronic Disease Dissemination Study. Psychometrics reported in: Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

Comments

This 6-item scale contains items taken from several SE scales developed for the Chronic Disease Self-Management study. We use this scale now, as it is much less burdensome for subjects. It covers several domains that are common across many chronic diseases, symptom control, role function, emotional functioning and communicating with physicians. For internet studies, we add radio buttons below each number. There are 2 ways to format these items. We use the format on this document, the other is shown on the web page. A 4-item version of this scale available in Spanish.

References

Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

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