GLOSSARY OF TERMS

TERMS WITH DESCRIPTIONS FOR USE IN CAREWELL DELIVERABLES

WP8 LEARNING FROM EACH OTHER & EXPLOITATION OF RESULTS

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STATEMENT OF ORIGINALITY

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

EXECUTIVE SUMMARY

During the CareWell project lifetime, we found that often the same, or very similar words and phrases, were used to describe different aspects and elements of integrated care and, on the contrary, a similar element could be named differently in different sites or documents. This Glossary has been developed to provide a common language and understanding for the complex landscape of integrated care across a number of European regions. It is based on the experience of three EU funded projects, SmartCare, BeyondSilos and CareWell. There is variation in the care infrastructure, workforce and legislative framework in the regions involved, which underpin collaborative working, which is considered a prerequisite to delivering integrated care services.

The formulation of the terms and their descriptions has been an iterative process with EU eCare enabled integrated care colleagues from the SmartCare, BeyondSilos and CareWell projects, together with external 'experts' who have provided a wider perspective than the focus of the projects themselves.

The Glossary outlines the integrated care terms from the following four dimensions:

- Care sectors and settings.
- Care provider organisations.
- People involved.
- Care pathway concepts, activities and components.
- ICT components.

The terms will be made available to the European Innovation Partnership on Active and Healthy Ageing, B3 Action Group on Integrated Care members. In addition, a Special Interest Group will be established under the International Foundation for Integrated Care Academy where any interested individuals will be able to collaborate on the further development of the Glossary and its alignment with other activities, striving to build a common language to support aspects of care.

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1 Introduction

1.1 Purpose of the document

During the Project's lifetime, we found that often the same, or very similar words and phrases, were used to describe different aspects and elements of integrated care and, on the contrary, a similar element could be named differently in sites or documents. This document provides details of the key terms and their descriptions to be used in compiling the CareWell project's final deliverables in order to ensure consistency in language and terms, and facilitate international knowledge exchange and understanding of the project. Furthermore, as part of the Synergies work package within the SmartCare project, the terms and descriptions developed in this CareWell deliverable are intended to promote a common understanding and language across these projects together with BeyondSilos.

1.2 Structure of the document

Section 2 provides the background and the requirement to develop the Glossary.

Section 3 presents the glossary terms from four different integrated care dimension.

Section 4 lists the sources used to compile the Glossary.

1.3 Abbreviations

The following abbreviations are referred to in this deliverable, some of which are well-recognised and frequently used in literature. They will be included in the Glossary section of CareWell final deliverables:

ADL	Activities of Daily Living
CC	Care Co-ordinator
CG	Caregiver
CP	Care Practitioner
CR	Care Recipient
CSW	Care Support Worker
EHR	Electronic Health Record
FC	Family Carer
GP	General Practitioner
HCP	Health Care Professional
HCPO	Health Care Provider Organisation
HCSW	Health Care Support Worker
IADL	Instrumental Activities of Daily Living
ICT	Information & Communication Technologies
IH&SCPO	Integrated Health & Social Care Provider Organisation
PHR	Personal Health Record
SCP	Social Care Professional
SCPO	Social Care Provider Organisation
SCR	Social Care Record
SCSW	Social Care Support Worker
SICR	Shared Integrated Care Record
TSPO	Third Sector Provider Organisation

2 Background

2.1 Introduction

It is widely understood that the reality of delivering integrated services is challenging and complex, with different accountabilities, priorities, pressures and needs that create tensions across any given health and care system. The CareWell pilot sites are testing a range of care models, working across the boundaries between primary, community, and secondary care services, and aligning their models to social care services. They are focused on developing integrated healthcare services facilitated by ICT for frail, *multi-morbid* older population groups at high risk of hospitalisation or dependency on formal care. The other two projects considered (SmartCare and BeyondSilos) also integrate social care.

The importance of developing a common language as well as a shared sense of purpose emerged as one of the lessons learned within the CareWell consortium and the pilot site stakeholders.

2.2 Approach

The first step in developing this glossary was undertaken via a literature search of existing glossaries on integrated care. This research highlighted the lack of comprehensive glossaries available, with a number focusing on providing an understanding of local integrated care initiatives and organisational configurations, rather than ensuring that there is clarity in terms and abbreviations used to distinguish and describe the different types of organisations and people involved in delivering integrated care services at national, regional and local level. Section 4 of this deliverable provides a list of resources which were reviewed to inform the Glossary.

The second stage involved a review of a number of deliverables produced for the CareWell, BeyondSilos and SmartCare EU funded integrated care projects. Final deliverables associated with the development of use cases, care workflow and pathways, together with service specification and ICT infrastructure, were examined to elicit the key terms used by each project in describing the organisational infrastructure, workforce and support care delivery components, as well as care process and ICT solutions. Consideration was given to the following:

- The terms used and their relevance to integrated care.
- Which words were used and how the terms were interpreted.

The next step involved grouping the terms and compiling suggested terms and descriptions for the most commonly used terms, paying attention to ensuring the term was suitable for health, social care and support services where appropriate.

A number of experts and representatives from the three projects, together with a group of interested individuals, accepted an invitation to comment and offer insights on the initial draft of the glossary during a workshop at the International Conference on Integrated Care in May 2016.

A second draft of the glossary was prepared, and presented in a teleconference to members of the CareWell consortium for their feedback, and then a final draft circulated at the PA meeting in Crete.

The final version detailed in this deliverable has consolidated the comments and provides a set of terms that can be used across Europe when describing many of the key components involved in delivering integrated care services.

3 Glossary of terms

3.1 Summary of terms defined

The glossary terms are described under five main themes associated with care delivery as follows:

- Care sectors and settings:
  - Primary Care
  - Secondary Care
  - Tertiary Care
  - Social Care
  - Community Care
  - Third Sector Care
  - Family Support & Care
- Care provider organisations:
  - Health Care Provider Organisation (HCPO)
  - Social Care Provider Organisation (SCPO)
  - Third Sector Provider Organisation (TSPO)
  - Integrated Health & Social Care Provider Organisation (IH&SCPO)
  - Care Recipient (CR)
  - Caregiver (CG)
  - Family Carer (FC)
  - Friend / Neighbour
  - Volunteer
- People involved:
  - Care Practitioner (CP)
  - Health Care Professional (HCP)
  - Social Care Professional (SCP)
  - Health Care Support Worker (HCSW)
  - Social Care Support Worker (SCSW)
  - Care Support Worker (CSW)
  - Care Co-ordinator (CC)
- Care pathway concepts, activities and components:
  - Care Process Pathway
  - Clinical Pathway
  - Clinical guideline
  - Needs assessment
  - Activities of Daily Living (ADI)
  - Instrumental Activities of Daily Living (IADL)
  - Care Plan
  - Integrated Care Plan
  - Integrated Health Services
  - Person-centred services / care
  - Care Coordination
  - Case Management
  - Multi-morbidity
  - Multi-disciplinary team
  - Polypharmacy
  - Rehabilitation
  - Risk Factor
  - Comprehensive Geriatric Assessment (CGA)
  - Self-management
  - Social Care
  - Social Network
  - Well-being
  - eHealth Call Centre
- ICT components:
  - Social Care Record (SCR)
  - Electronic Health Record (EHR)
  - Shared Integrated Care Record (SICR)
  - Personal Health Record (PHR)
  - Telehealth
  - Telecoaching
  - Telecare
  - Assistive technologies
  - Platform
  - Portal
  - Application

Terms defined here are shown in italics when referenced elsewhere within the text.

3.2 Care sectors and settings

The care, treatment and support for frail, *multi-morbid* older people usually involves care practitioners from different care sectors working together effectively. Integrated healthcare delivery models usually position multidisciplinary and sometimes

interdisciplinary teams as the cornerstones of successful care service provision within and across the different care sectors and settings listed in Table 1 below.

Table 1: Care sectors and settings

Term	Description	Examples
Primary Care	Day-to-day healthcare given by a healthcare provider who typically acts as the first contact and principal point of providing care continuity for patients.	General Practice which can include home visiting nurses Pharmacy Opticians Dental Practice
Secondary Care	Specialist healthcare services, care, treatment and support often provided in a hospital care setting, but also in an ambulatory / community-based care centre.	Inpatient services Outpatient services Diagnostic tests and procedures Emergency services
Tertiary Care	Highly specialised healthcare services usually provided in regional centres of excellence.	Hospitals
Social Care	Home and community-based services to support people with personal and practical help for activities of daily living to maintain their independence.	Home help Supported living
Community Care	Services, care, treatment and support to help people with care needs to live as independently as possible in the home of their choice and community. The workforce members may be employed by GP practices, health or social care authority / organisation.	Home-visiting nursing services Physiotherapy Occupational Therapy Social support
Third Sector Care	Paid or unpaid care and support provided by volunteers registered with or paid employees of a third sector organisation.	Red Cross Alzheimer's Association
Family Support & Care	Care and support given by people nominated by the Care Recipient or their named family carer.	Family members Friends and neighbours

3.3 Care provider organisations

Within the different care sectors, there are a number of care provider organisations that contribute to the delivery of integrated healthcare services. Defining and describing these care provider organisations helps to assess and understand the services offered, and the governance and funding models associated with the organisation and its staff. In turn, this information assists in determining which organisation is best placed to deliver specific services across the care system sectors.

Table 2: Care provider organisations

Term	Abbreviation	Description	Examples
Health Care Provider Organisation	HCPO	An organisation that has been commissioned or contracted to deliver what the region considers is health care services and / or support	Hospital Health Authority Health Board Managed care organisation GP practices
Social Care Provider Organisation	SCPO	An organisation that has been commissioned or contracted to deliver what the region considers to be social care services and / or support	Municipality / Local Authority Third sector organisation Private care provider
Third Sector Provider Organisation	TSPO	An organisation that provides care and support through registered volunteers without a formal contract with either HCPO or SCPO	Red Cross Alzheimer's Association
Integrated Health & Social Care Provider Organisation	IH&SCPO	An organisation that has been commissioned or contracted to deliver what the region considers to be both health and social care services and/or support, and whose staff are employees	Eksote, South Karelia, Finland Health & Social Care Board, Northern Ireland Badalona Serveis Assistencials SA, Spain TioHundra, Sweden

3.4 People

It is usually the case that frail, *multi-morbid* older people receive care, treatment and support from a number of individuals. These people often have different job titles, roles and responsibilities, depending on which organisation they belong to in their European region.

The CareWell project focuses on providing people-centred, integrated healthcare pathway services, and has required *care practitioners*, together with the *care recipient* and their *family carers*, to not only work as part of a multidisciplinary team, but also seek and share relevant information to ensure care recipients' care, treatment and support is optimised. Furthermore, the team approach shares responsibility and accountability for the delivery of the *care pathway* clinical processes and outcomes at a *care recipient*, community and population level.

The following tables divide the different people into those chosen by or related to the frail older person (Table 3) and those who receive a payment from an organisation to provide a care pathway activity (Table 4).

Table 3: People chosen by or related to the frail older person; sometimes referred to as informal carers

Term	Abbreviation	Description	Synonyms used in relevant care settings
Care Recipient	CR	An individual who receives or seeks any care services or support considered to be integrated care, from another person or organisation. In certain circumstances, a Care Recipient may be the term used for a person receiving a new project-based service.	Patient Service User Client / End User Customer Individual Person
Caregiver	CG	Generic description of a person who provides care and support to someone else in either a paid or unpaid capacity. Such support may include: • Helping with self-care, household tasks, mobility, social participation and meaningful activities. • Offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision-making. • Offering respite services. • Engaging in activities to foster intrinsic capacity.	Carer Friends and neighbours Volunteers Personal Carer Personal Assistant Informal Carer
Family Carer	FC	Family carer (relative) who is unpaid (role may be supported by government funding).	Caregiver Informal Carer
Friend / Neighbour		Person associated through an affectionate bond, or living in the neighbourhood, agreed by the Care Recipient and/or family, who provides care and/or support, and who is unpaid.	Caregiver Informal Carer
Volunteer		An individual who is registered in any organisation to deliver care, services, or support to a Care Recipient.	Caregiver Informal Carer

Table 4: People who receive a payment from an organisation to provide a care pathway activity; sometimes referred to as 'formal' carers

Term	Abbreviation	Description	Examples used in relevant care settings
Care Practitioner	CP	A generic term to describe an individual who is employed by any organisation to deliver care, services, treatment or support to a Care Recipient. This term includes all of the workforce people below.	

Term	Abbreviation	Description	Examples used in relevant care settings
Health Care Professional	HCP	An employed individual who is professionally educated and trained to deliver care, services, treatment or support to a Care Recipient. These employees are registered with professional bodies and are required to renew their professional accreditation regularly.	Clinicians Doctors Nurses Allied Health Professionals
Social Care Professional	SCP	An employed individual who is professionally educated to deliver social care services and support to a Care Recipient.	Social Worker Link Worker
Health Care Support Worker	HCSW	An employed individual who is qualified to deliver care, services, treatment or support to a Care Recipient.	Health Care Assistant Nursing Assistant
Social Care Support Worker	SCSW	An employed individual who is qualified to deliver care, services, treatment or support to a Care Recipient.	Home Carer Liaison Officer
Care Support Worker	CSW	An individual who is qualified and employed by a third sector organisation to deliver care, services or support to a Care Recipient.	Befriender Patient transport driver
Care Co-ordinator	CC	An individual who is responsible for co-ordinating the care and support of a Care Recipient. Could be a role undertaken by any of the above, or the Care Recipient or family carer.	Advanced Care Practitioner Care Transition Nurse Liaison Nurse Case Manager Co-ordinator

3.5 Care pathway concepts, activities and components

For more than a decade, most European regions have used a care pathway and guidelines approach to underpin the delivery of many healthcare services, particularly those for people living with chronic conditions. There is a growing evidence base of organisations' experience of developing and using care pathways in terms of the approach leading to better quality of care and improved care transitions between *care practitioners* and provider organisations. CareWell, as well as BeyondSilos and SmartCare, has adapted the care pathway approach to describe and document the vertically integrated care process to meet the holistic needs of *care recipients*. Table 5 below provides descriptions of different care pathway terms together with the key activities and components included in the pathways developed within the CareWell project:

Table 5: Care pathway concepts, activities and components

Term	Description	Synonyms
Care Process Pathway	Pathway that maps out a Care Recipient's journey from entry to discharge through the care system in terms of how the different care practitioners collaborate to assess, plan, deliver, monitor and review care, services and support.	Care pathway Chain of Care
Clinical Pathway	Standardised, evidence-based multidisciplinary management plan, which identify an appropriate sequence of **clinical** interventions, timeframes, milestones and expected outcomes for a homogenous patient group.	Disease pathway
Clinical guideline	Set of systematically developed statements to assist the decisions made by care practitioners about healthcare activities to be performed with regard to specified health issues: • They are generally based on evidence and good practice, and may sometimes include multiple operational details. • Clinical guidelines are structured and contain standard criteria and indicators for measurement. • Guidelines can also address aspects of care and treatment that are controversial, complex or critical for the care recipient prognosis.	Care guideline
Activities of Daily Living (ADLs)	The basic actions necessary for everyday life functioning such as bathing or showering, dressing, eating, getting in or out of bed or chairs, using the toilet, getting around inside the home. It is a measurement of functional status.	Daily basic self-care tasks
Instrumental Activities of Daily Living (IADLs)	Activities that facilitate independent living such as using the telephone, taking medications, managing money, shopping for groceries, preparing meals. They are not necessary for basic life functioning, but assist an individual to live independently in a community.	Tasks to live independently in the community

Term	Description
Care Plan	A dynamic, personalised plan designed to co-ordinate care for an individual Care Recipient. It includes identified needed healthcare activities, health objectives and healthcare goals, relating to one or more specified health issues in a healthcare process. • A care plan may be recorded in one or more health records. • A care plan could be subdivided into different perspectives by different constraints. One example is uni-professional care plan, for example, a nursing care plan. • Care plans are reviewed repeatedly during a healthcare process, each review based on a new needs assessment. • The healthcare activities in a care plan follow a life cycle. Examples of statuses of such a life cycle are: 'planned', 'performed', 'cancelled', etc.; all of these are included in the care plan.

Term	Description
Integrated Care	A coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction, and system efficiency for people by cutting across multiple services, providers and settings. Where the results of such multi-pronged efforts to promote integration lead to benefits for Care Recipients, the outcome can be called 'integrated care'
Integrated Care Plan	A Care Recipient's Care Plan providing comprehensive information on the on-going and future care services, treatment and support from all organisations and Caregivers involved, which may or may not be shared with the Care Recipient.
Integrated Health Services	Integrated health services are managed and delivered in a way that ensures people receive a continuum of services including health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care at different levels and sites within the health system; the care is provided according to the Care Recipient's needs.
Person-centred services / care	An approach to care that consciously adopts the perspectives of individuals, families and communities. It is organised around the health needs and expectations of people rather than diseases. It sees people as participants as well as beneficiaries of healthcare and long-term care systems that respond to their needs and preferences in humane and holistic ways. It ensures that people-centred care is delivered, and requires that ideally people have the education and support they need to make decisions and participate in their own care.
Care Coordination or Coordination of Care	Organisation and delivery of the Care Recipient's services, care, treatment and support activities when there are two or more participants (in addition to the Care Recipient). It facilitates the appropriate delivery of the care plan. It is a function that can be undertaken by a member of the care team with or without ICT support, and can be documented in the care plan.
Case Management	The delivery of planned services through collaborative processes to meet a Care Recipient's health needs through communication with the person and their service providers and coordination of resources.
Multi-morbidity	The co-occurrence of two or more long-term (chronic) medical conditions in one person.
Multi-disciplinary team	A team of Care Practitioners with different professional backgrounds and roles, who convene to assess a Care Recipient's needs, agree the Integrated Care Plan, monitor the delivery of the Care Plan and review or re-assess the Care Recipient's needs regularly. The Care Recipient and Family Carers are sometimes included in the team.
Polypharmacy	Polypharmacy, or inappropriate drug use, is a term used to describe the prescribing of four (some authors establish six) medications, leaving a patient at risk of overdose, harmful drug interactions, and potential adverse side effects. Polypharmacy can occur in a variety of ways: • Prescribing an inappropriately high number of medications. • Prescribing two or more meds to treat the same condition. • Excessive dosages[1].

[1] Bushardt RL, Massey EB, Simpson TW, Ariail JC, Simpson KN. Polypharmacy: Misleading, but manageable. Clinical Interventions in Aging. 2008;3(2):383-389.

Term	Description
Rehabilitation	Rehabilitation is a term used to describe a broad range of interventions that result in the improved physical, mental and social well-being of those suffering from injury, illness or chronic disease.
Risk Factor	A risk factor is an attribute or exposure that is causally associated with an increased probability of a disease or injury.
Self-management	Activities carried out by individuals to promote, maintain, treat and care for themselves, as well as to participate in shared decision-making about their health and wellbeing.
Social Care	Home and community-based services to support people with personal and practical help for activities of daily living to maintain their independence.
Social Network	An individual's web of kinship, friendship and community ties.
Well-being	Well-being is about feeling good and functioning well and comprises an individual's experience of their life; and a comparison of life circumstances with social norms and values.
Call Centre	A centralised ICT supported team of people employed by a care provider organisation, who are usually responsible for receiving or transmitting information for monitoring, handling, and responding to any on-line or phone health requirements, alerts or alarms from technologies such as e-messaging, telehealth, telecare, or assistive technology deployed into a Care Recipient's home.
Comprehensive Geriatric Assessment (CGA)	A multidimensional appraisal/evaluation of an older person that includes medical, physical, cognitive, social and spiritual components. It may also include the use of standardised assessment instruments and an interdisciplinary team to support the process.

3.6 ICT components

Within the CareWell project, some of the interventions to promote patient-empowerment and coordination of care have been enhanced through the implementation of ICT components, particularly widening the use of and access to electronic care records, and mobile and internet-based services to provide *care recipients* and *care practitioners* with more timely information exchange. Table 6 below describes the different electronic care records used in many CareWell pilot sites, together with the abbreviation used for the respective electronic care record. Table 7 defines the key CareWell technology component terms and their respective descriptions:

Table 6: Information, communication and technology record components

Term	Abbreviation	Description	Examples
Social Care Record	SCR	An SCR contains standard information relating to the referral, assessment and care package delivered to a care recipient.	
Electronic Health Record	EHR	A longitudinal health record, in a digital (electronic) format, that incorporates data and information from all medical and clinical services and care delivered by a healthcare provider organisation or region. The electronic record may be shared across care settings and between care practitioners.	GP electronic record Hospital electronic health record

Term	Abbreviation	Description	Examples
Shared Integrated Care Record	SICR	An electronic care record that contains the relevant data and information for health and social care services and support delivered by all care practitioners and shared between them.	
Personal Health Record	PHR	A person-held or controlled electronic record / folder, with much information coming from the EHR, that can be shared with Care Practitioners and other people nominated by the Care Recipient. The Care Recipient is able to view and add information to their PHR.	Person held record Personal health folder

Table 7: Key CareWell technology components

Term	Description	Examples
Telehealth	Remote physiological measurement and symptom management monitoring and support for self-management.	Telemonitoring applications to monitor blood pressure, oxygen saturation, etc.
Telecoaching	Remote technology-enabled health guiding or tutoring.	On line patient empowerment functionalities
Telecare	Remotely monitored attention and support for elderly and less able people by means of alarms, sensors and other equipment connected to a Call Centre.	Panic button Smoke alarm Falls detector
Assistive technologies	Any device designed, made or adapted to help a person perform a particular task, enhancing the capacity to run an independent life. Products may be generally available, or specifically designed for people with specific losses of capacity.	Stair lift Walking aids
Platform	A foundation infrastructure component (hardware, browser, operating system) able to host software applications.	Windows Living it Up Whaiora Online
Portal	A web access user interface to connect and view the content of online applications, as well as ability to download content.	Living it Up
Application (App)	Software to deliver end user functionality; it often operates on a variety of platforms (mobile phone, tablet, PC).	MyChart, UpToDate, webMD, Personal health folder App

4 Sources used to compile glossary

This CareWell Glossary of Terms was compiled using the following sources of information to inform its development:

- CareWell deliverables:
  - D2.2 Use cases for integrated care models and pathways
  - D3.2 Organisational and service process models
  - D4.2 Pilot level service specification for CareWell services
- BeyondSilos deliverables:
  - D1.2 Pilot level pathways & Integration Infrastructure
  - D2.1 Organisational & Service Process Models
  - D3.2 The BeyondSilos Service Specification
- SmartCare deliverables:
  - D1.2 Pilot-level pathways and integration infrastructure
  - D2.1 SmartCare service process models
  - D3.2 Final Service specification
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